Inventory of Profiles

Existing Patient Identification Systems with Ethnocultural Identifiers Specific to First Nations, Inuit, and Métis Peoples in Canada

Canadian Partnership Against Cancer

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The Bridge Consulting Group

Strategy and organizational
change facilitation

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1.0 ACKNOWLEDGEMENTS

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2.0 INTRODUCTION

2.1 First Nations, Inuit, and Métis Action Plan on Cancer Control

The Canadian Partnership Against Cancer (Partnership) was established by the federal government to shape and oversee implementation of a national control strategy that will significantly reduce the impact of cancer on all Canadians. The Partnership works with provincial/territorial governments, provincial cancer agencies and programs, federal agencies, patient groups, professional associations, national cancer organizations and others to bring Canada's cancer control strategy to life and create a more coordinated and efficient cancer control system. Being culturally responsive to the needs of First Nations, Inuit and Métis peoples is an important priority within this work.

The Partnership recently facilitated the development of the *First Nations, Inuit and Métis Action Plan on Cancer Control*, in collaboration with First Nations, Inuit and Métis peoples, patients and organizations involved in cancer control and chronic disease prevention. The Action Plan has been endorsed by national Aboriginal organizations - Assembly of First Nations, Inuit Tapiriit Kanatami and Métis National Council - as well as the Partnership's Advisory Committee on First Nations, Inuit and Métis Cancer Control. The advisory committee includes representatives from the Public Health Agency of Canada, First Nations and Inuit Health Branch, Canadian Association of Provincial Cancer Agencies, Canadian Cancer Society, as well as patients and First Nations, Inuit and Métis elders.

Implementation of the Action Plan is now underway. The 2011/2012 focus is on gathering information (data and resource/program collation) to provide a knowledge development foundation that will enable longer term collaborative work in the Partnership's second mandate, including facilitating adoption of leading practices that are culturally responsive and address identified priorities.

The 2011/2012 work includes the Environmental Scan and Analysis of Existing Patient Identification Systems for First Nations, Inuit and Métis peoples. The goal of this project is to identify existing systems of patient identification specific to First Nations, Inuit and Métis ethnicity, and to analyze barriers to developing common standards for data collection, access and reporting. The Partnership's 2011/12 action plan includes a commitment to document existing systems of ethno-cultural patient identification for First Nations, Inuit, and Métis populations, and to analyze and identify leading practices.

The longer term impact the Partnership pursues is to improve the ability to collect baseline information (i.e. incidence, care patterns and outcomes), and thus target services to areas of most need, leading to improved cancer care for and with First Nations, Inuit and Métis peoples.

2.2 About the Inventory of Profiles

We estimate that there are thousands of health information holdings currently in use across Canada. These holdings contain structured health and health-related data (e.g. insurance, demographics) in an electronic format. They are used every day by clinicians, administrators, researchers and policy makers to make decisions that affect patients as well as healthy people. To our knowledge, there is no database of health databases, one that systematically describes and updates Canada's health information holdings.

This inventory of profiles is intended to start to fill a gap in the identification and systematic description of Canadian health data holdings that contain First Nations, Inuit and/or Métis identifiers. It aims to do so in two ways. Firstly, by offering a structured profile format that allows for capturing the salient features of health data bases with ethnocultural identifiers. Secondly, by applying this profile format to describe a range of health databases across Canada that includes Aboriginal, First Nations, Inuit and/or Métis identifiers. This inventory includes forty two of these data holdings as well as eight practices that can support the inclusion of ethnocultural identifiers in health databases. They were identified through an environmental scan whose methodology is described in the companion report to this inventory.

This inventory presents a collection of good and emerging practices for including First Nations, Inuit and/or Métis identifiers in health data bases. It is intended primarily for participants in the evolving dialogue about equitable health care and the role of ethnocultural information, who wish to build on the experience of others. The profile format is a first step, and not intended to be definitive. The inventory is not complete, merely a first overview of noteworthy practices from across Canada at this point in time - in a dynamic and fast-changing health information environment.

2.3 Content and Organization

The information in this inventory is arranged according to geographic scope. Each entry includes sections on:

I. The database, including a general description of the holding, and ethnocultural identifiers available;

II. Data design, collection, recording and storage practices, including the ethnocultural identity question used;

III. Data access practices, including privacy constraints and First Nations, Inuit and Métis engagement processes; and

IV. Data use and reporting practices, including thoughts on the potential application to other jurisdictions.

The inventory includes cross-referencing charts to help the reader to locate individual information holdings by title (alphabetical), and by geography, identifier, service domain and source of the ethnocultural identifier.

This inventory is accompanied by a separate analytical report titled "Where there's a will, there's a way … Environmental scan and analysis of existing patient identification systems for First Nations, Inuit and Métis peoples".

2.4 Comments

The Canadian Partnership Against Cancer welcomes comments or additional information to contribute to this inventory. Please write to First Nations, Inuit and Métis Cancer Control, Canadian Partnership Against Cancer at info@cancerview.ca.

2.5 How to Read This Inventory

The profiles are laid out according to one of two formats: DCF (Data Collection Form) v2.0-S for single source databases, and DCF v2.0-M for multi-source databases. DCFv2.0-S is detailed on pages 16 - 19, including the definition for each field. DCFv2.0-M is included in the Appendix.

Eight profiles presented in this inventory do not describe databases, but practices that support or enable the creation and use of health databases with ethnocultural identifiers. These enabling practices include

4.1.1. Aboriginal Administrative Data Standard: a data standard to enable consistency in the way the B.C. government promotes identification of aboriginal citizens;

4.1.2 Indigenous Cultural Competency: a training program designed to increase Aboriginal-specific knowledge, enhance individual self-awareness and strengthen skills for non-Aboriginal health care leadership, professionals and service providers.

4.1.5 The Mustimuhw cEMR is a client information management system, designed specifically for First Nation Health Centres; this community Electronic Medical Record (cEMR) is currently deployed in over 50 First Nations/ site in three provinces: British Columbia, Manitoba and Saskatchewan.

4.1.6 Tripartite Political Process: summarizes aspects of the history of tripartite and bipartite political processes involving First Nations and Métis peoples in British Columbia. These political processes are judged to be relevant to the objective of this report;

4.4.1 Aboriginal Identity Indicator in Cancer Patients – a protocol for collecting Aboriginal identity indicators in cancer patients attending a specialized cancer centre. While there is a relatively small database associated with this work, the long term value of this project is in the extensive documentation of the processes used, the evaluation of these processes, and the resulting protocol;

4.7.2 Newfoundland and Labrador Aboriginal Administrative Data Identifier: a provincial project initiated by the Department of Health and Community Services, who established a provincial working group in January 2010 to work towards a provincial data standard for Aboriginal identification within key health information systems, as well as a plan for implementation. As of November 2011, the proposed standard is being submitted to the Department of Health and Community Services, Government of Newfoundland and Labrador for approval, which will involve cross-ministerial review;

5.3.1 Ethnicity Reference Set: a value set that supports the pan-Canadian Primary Health Care Content Standard to enable consistency in the way ethnicity is captured in Canadian electronic medical records.

5.7.5 Longitudinal Health and Administrative Data Initiative: this is a partnership that allows for linking provincial/ territorial health administrative databases to existing Statistics Canada data to effectively answer important health policy questions in a cost-efficient manner. LHAD is not a database. Rather, it is a process or mechanism to enable high quality, timely and cost-efficient linkage of existing databases for the purpose of statistical research. The participating databases remain with their own custodians. The LHAD initiative allows linkage through the creation of a key registry.

The above eight initiatives represent enabling work towards (i) data standards, guidelines for collecting, storing, accessing and using data, and processes to harmonize the linkage between existing data holdings, and (ii) practices that aim to improve awareness of the importance and use of ethnocultural identifiers, and offer relevant training in this area. In most cases, the Data Collection Form that was developed for this project was an effective way to capture information about these enabling practices too. The exceptions are the write-ups of the Indigenous Cultural Competency and Tripartite Political Processes, which have been included as plain text. All the Profiles are presented with a view to contributing towards an experience-informed discussion on options to achieve better identification of First Nations, Inuit and Métis people in Canadian health databases.

I. DATABASE – [Actual name given by Custodian]

Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	Summary of description of the database
Custodian	Name of organization that holds database
	Mandate of Custodian: Please specify
Purpose	Principal decision(s) or activities that the information is intended for (in your words)
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☐ Database includes demographic data
	☐ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/ Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	Comments (Optional)
Status & Update	Database status Select One (Active; Inactive)
	Database update frequency Select One Frequency of Updates: (1-off; Ad-hoc, but > 1; On-going/ on regular frequency)
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Month/year of latest available ethno-cultural identifiers:
Level of Detail	1. Select One (Individual record; Aggregate) 2. If Individual Record was selected: Select One (Identifiable; Not identifiable) 3. If Not identifiable was selected: Select One (Reversible; Not reversible)
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Specify
	Select One (Municipality; Forward Sortation Area; Census Tract; Dissemination Area; Postal Code)
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease

I. DATABASE – [Actual name given by Custodian]

Users	Primary users of this database - A short list of key users
	Select One (Only users internal to Custodian use the database; Database also used by users external to Custodian)
Populations	Population groups included in this database – A short list of key populations
	Population Coverage - % of population targeted by the database that has been captured: Example: this provincial cancer registry captures around x% of all incident cancer cases
	Alternatively, sample with weights? Select One . (Yes; No) If yes, sample size % of population
Records	Total # of records in database: Annual number of records collected/updated:
Contact/ Questions	Support Organization Title of person in support role: Name: Phone: E-mail:
Web site	URL for further information

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached
Question Design	Reason why the above question and/or identifier was chosen: Please describe
	Ethno-cultural identity question(s) has been tested Select One (Yes; No) Test report re question design is available Select One (Yes, No) Name/citation for test report:
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Select One , (No; Yes) If yes, barriers/gaps that have been addressed: Please describe
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One (Yes; No) Test /pilot/ evaluation report is available Select One (Yes; No) Title/ citation for report:
Data Linkage	<u>Potential</u>, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Select One (Answer 1; 2; 3; 4) 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One (Yes; No)
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One (Yes; No)
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One (Yes; No)
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One (Yes; No)
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One (Yes; No)
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality (optional)	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One (Yes; No) Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Select One (Yes; No) Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database
	A Privacy Impact Assessment has been done for this database Select One (Yes; No: Not Applicable)
	Information has been used for secondary purposes Select One (Yes; No; Not Applicable) If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Select One (Yes;No:Not Applicable) An MOU or formal agreement governing development and/or use of the database is in place Select One (Yes; No; Not Applicable) First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One (Yes; No; Not Applicable) Inuit Land Claims research protocols Select One (Yes: No; Not Applicable) Métis requirements Select One (Yes; No; Not Applicable)

IV. DATA USE & REPORTING	
Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One (Yes; No) Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One (Yes; No) Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One (Yes; No) Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One (Yes; No) Comments (optional)
	Thoughts/advice on factors that would <u>Support</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment <u>Limit</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

3.0 CROSS REFERENCE CHARTS

Cross Reference Chart I

		Identifier									Service Domain															Geography													
Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
PROVINCIAL / TERRITORIAL, REGIONAL / LOCAL																																							
British Columbia																																							
▪ Aboriginal Administrative Data Standard	31	●	●	●	●	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●												
▪ Indigenous Cultural Competency [1]	38										●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●		●	●	●							
▪ Interior Health – Aboriginal Self Identification Project [2]	40	●	●	●	●	●		●	●		●	●															●												
▪ Métis Nation British Columbia Central Registry	46								●																		●												
▪ Mustimuhw cEMR	53	●	●	●	●	●	●								●			●	●			●		●	●		●		●	●									
▪ Tripartite & Bipartite Political Processes	62																										●												
Saskatchewan																																							
▪ Métis Nation Saskatchewan Citizenship Registry	69								●																				●										
Manitoba																																							
▪ Manitoba Métis Federation Membership Registry	76								●																					●									
▪ Manitoba Métis Population Database	83								●		●				●			●	●	●	●	●	●	●						●									
▪ Registered First Nations & Manitoba Health Insurance Registry Linkage	89	●	●		●	●	●				●	●	●	●	●	●	●	●	●	●	●	●	●	●	●					●									

Cross Reference Chart I

		Identifier									Service Domain															Geography													
Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
Ontario																																							
▪ Aboriginal Identity Indicator in Cancer Patients - Protocol	98	●	●	●	●	●		●	●	●											●										●								
▪ Better Outcomes Registry & Network (BORN)	104	●	●	●	●	●		●	●	●	●								●												●								
▪ Colorectal Cancer Screening Registry	109																				●										●								
▪ Métis Nation Ontario Citizenship Registry	116								●																						●								
▪ Ontario Cancer Registry/Indian Register Linkage (1968-2001)	124	●	●																		●										●								
▪ Our Health Counts – Baseline Population Health Database for Urban Aboriginal People in Ontario	128	●	●	●		●	●				●	●			●				●	●	●	●	●	●	●						●								
▪ Tri-Hospital Health Equity Data Collection Project	134	●		●				●	●	●	●				●				●						●						●								
Quebec																																							
▪ Nunavik Inuit Beneficiaries List	140							●																								●							
▪ Register of Cree, Inuit and Naskapis	148	●	●					●																								●							
Nova Scotia																																							
▪ Colon Cancer Screening Registry	154	●																			●													●					
▪ Unama'ki Client Registry & Data Linkage Model	160	●	●	●	●	●	●				●	●			●				●	●	●	●												●					

Cross Reference Chart I

		Identifier									Service Domain															Geography													
Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
Newfoundland and Labrador																																							
Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement	167							●																												●			
Newfoundland and Labrador Aboriginal Administrative Data Identifier	173	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●											●			
Northwest Territories																																							
Inuvialuit Regional Corporation Enrolment Registry	180							●																														●	
Northwest Territories Cancer Registry	188	●	●					●	●												●																	●	
Northwest Territories Health Care Plan Client Registry	193	●	●					●	●	●	●	●		●	●	●	●	●	●	●	●	●	●	●	●													●	
Northwest Territories Vital Statistics Registry	200	●	●					●	●																													●	
Nunavut																																							
Nunavut Cancer Registry	205	●						●	●												●																		●
Nunavut Health Care Plan Client Registry	209	●	●					●	●		●	●		●	●	●	●	●	●	●	●	●	●	●	●														●
Nunavut Inuit Enrolment List	214							●																															●
Nutaqqavut 'Our Children' Health Information System	219	●						●	●		●								●																				●

Cross Reference Chart I

		Identifier									Service Domain															Geography													
Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
NATIONAL																																							
National First Nations, Inuit and Métis Databases																																							
▪ First Nations Regional Health Survey	227	●	●		●		●								●	●		●	●		●	●				●	●	●	●	●	●	●	●	●	●	●	●	●	
▪ Inuit Health in Transition Study	233							●							●							●														●		●	●
▪ Urban Aboriginal Peoples Study	238	●	●	●		●		●	●																		●	●	●	●	●	●		●					
Aboriginal Affairs and North Development Canada																																							
▪ Indian Registry System	247	●	●		●	●	●																			●													
Canada Health Infoway																																							
▪ Electronic Medical Record: Ethnicity Reference Set	257	●						●	●										●							●													
Canadian Institute for Health Information																																							
▪ Canadian Organ Replacement Register	263									●													●			●													
▪ Continuing Care Reporting System[3]	269	○					●	○	○				●				●										●		●	●	●			●		●	●		
▪ Home Care Reporting System	274									●								●									●	●	●	●	●			●			●		
▪ National Rehabilitation Reporting System	279									●				●													●	●	●	●	●		●	●	●	●			
▪ Ontario Mental Health Reporting System	283									●					●																●								

Cross Reference Chart I

Information Holding Name	Page	Identifier									Service Domain															Geography													
		First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
▪ Primary Health Care Voluntary Reporting System	290	●						●	●										●								●			●	●					●			
Health Canada – First Nations and Inuit Health Branch																																							
▪ Status Verification System	298	●	●				●	●												●						●													
Health Canada – Public Health Agency of Canada																																							
▪ Canadian Chronic Disease Surveillance System [4]	303	●	●								●								●			●				●	●												
▪ Canadian Tuberculosis Reporting System	308	●	●	●	●	●		●	●	●															●	●													
Statistics Canada																																							
▪ Aboriginal Peoples Survey [5]	314	●	●	●		●	●	●	●																	●													
▪ Canadian Community Health Survey	321	●						●	●	●	●	●			●			●	●	●	●	●		●	●	●													
▪ 1991 Canadian Census Cohort: Mortality, Cancer & Residential Mobility Follow-up Study	327	●	●	●	●	●	●		●												●					●													
▪ Census – Long Form	331	●	●	●	●	●	●	●	●	●																●													
▪ Longitudinal Health and Administrative Data Initiative [6]	339	●	●	●	●	●		●	●		●	●			●					●	●					●				●	●								

Notes

1) To-date, the Indigenous Cultural Competency program has been delivered to participants from B.C., Alberta, Manitoba, Ontario, and Québec.
2) Longer term roll-out target would expand aboriginal self-identification to all Interior Health clients across all service domains.
3) The question underlying this information is expected to be changed in 2012-2013 to: "Client identifies self as First Nations (yes, no), Métis (yes, no), Inuit (yes, no).
4) Aboriginal component to CCDSS is exemplified in British Columbia and Newfoundland & Labrador data sets.
5) The 2006 Aboriginal Peoples Survey asks about membership in Indian Band or First Nation.
6) As of September 8, 2011, Ontario and Manitoba have signed partnerships in the Longitudinal Health and Administrative Initiative.

Cross Reference Chart II: Source File for FNIM Identifier		Self-Identification occurs at the time of					Comments
Information Holding Name	Page	Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
PROVINCIAL / TERRITORIAL, REGIONAL / LOCAL							
British Columbia							
▪ Interior Health – Aboriginal Self Identification Project	40				●		Initiative also includes employee self-identification.
▪ Métis Nation British Columbia Central Registry	46			●			
▪ Mustimuhw cEMR	53					●	
Saskatchewan							
▪ Métis Nation Saskatchewan Citizenship Registry	69			●			
Manitoba							
▪ Manitoba Métis Federation Membership Registry	76			●			
▪ Manitoba Métis Population Database	83	●		●			
▪ Registered First Nations & Manitoba Health Insurance Registry Linkage	89			●			
Ontario							
▪ Aboriginal Identity Indicator in Cancer Patients - Protocol	98					●	
▪ Better Outcomes Registry & Network (BORN)	104					●	Maternal Aboriginal identity field developed, but hidden pending successful completion of stakeholder engagement.
▪ Colorectal Cancer Screening Registry	109						Screening maps use Geospatial Analysis tool (cf Profile).
▪ Métis Nation Ontario Citizenship Registry	116			●			

Cross Reference Chart II:
Source File for FNIM Identifier

Information Holding Name	Page	Self-Identification occurs at the time of					Comments
		Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
▪ Ontario Cancer Registry/Indian Register Linkage (1968-2001)	124			●			
▪ Our Health Counts – Baseline Population Health Database for Urban Aboriginal People in Ontario	128	●					
▪ Tri-Hospital Health Equity Data Collection Project	134				●	●	Also being tested via patient electronic interface, and at bedside.
Quebec							
▪ Nunavik Inuit Beneficiaries List	140			●			
▪ Register of Cree, Inuit and Naskapis	148			●			
Nova Scotia							
▪ Nova Scotia - Colon Cancer Screening Registry	154				●		Participant form is mailed to eligible Nova Scotia residents.
▪ Unama'ki Client Registry & Data Linkage Model	160			●			
Newfoundland and Labrador							
▪ Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement	167			●			
▪ Newfoundland and Labrador Aboriginal Administrative Data Identifier	173						Best option to be determined.
Northwest Territories							
▪ Inuvialuit Regional Corporation Enrolment Registry	180			●			
▪ Northwest Territories Cancer Registry	188		●				
▪ Northwest Territories Health Care Plan Client Registry	193		●				
▪ Northwest Territories Vital Statistics Registry	200				●		

Cross Reference Chart II: Source File for FNIM Identifier

Information Holding Name	Page	Self-Identification occurs at the time of					Comments
		Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
Nunavut							
▪ Nunavut Cancer Registry	205		●				
▪ Nunavut Health Care Plan Client Registry	209		●				
▪ Nunavut Inuit Enrolment List	214			●			
▪ Nutaqqavut 'Our Children' Health Information System	219		●			●	
NATIONAL							
National First Nations, Inuit and Métis Databases							
▪ First Nations Regional Health Survey	227	●					
▪ Inuit Health in Transition Study	233	●					No specific screening question was used to identify Inuit community members. A list of Inuit residents in each community was generated based on community informants.
▪ Urban Aboriginal Peoples Study	238	●					
Aboriginal Affairs and North Development Canada							
▪ Indian Registry System	247			●			
Canada Health Infoway							
▪ Electronic Medical Record: Ethnicity Reference Set	257					●	
Canadian Institute for Health Information							
▪ Canadian Organ Replacement Register	263					●	
▪ Continuing Care Reporting System	269					●	

Cross Reference Chart II:
Source File for FNIM Identifier

Information Holding Name	Page	Self-Identification occurs at the time of					Comments
		Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
▪ Home Care Reporting System	274					●	
▪ National Rehabilitation Reporting System	279					●	
▪ Ontario Mental Health Reporting System	283					●	
▪ Primary Health Care Voluntary Reporting System	290					●	
Health Canada – First Nations and Inuit Health Branch							
▪ Status Verification System	298			●			
Health Canada – Public Health Agency of Canada							
▪ Canadian Chronic Disease Surveillance System	303		●	●			
▪ Canadian Tuberculosis Reporting System	308					●	
Statistics Canada							
▪ Aboriginal Peoples Survey	314	●					
▪ Canadian Community Health Survey	321	●					
▪ 1991 Canadian Census Cohort: Mortality, Cancer & Residential Mobility Follow-up Study	327	●					
▪ Census – Long Form	331	●					
▪ Longitudinal Health and Administrative Data Initiative	339	●					Data custodians can also bring their own data into the LHAD environment.

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.1 BRITISH COLUMBIA

4.1.1 Aboriginal Administrative Data Standard

I. DATABASE –	**Aboriginal Administrative Data Standard**
Geography	☐ Canada ☒ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The British Columbia Aboriginal Administrative Data Standard (AADS) is a guide to ministries and affiliated agencies to support the collection of self-reported data on Aboriginal identity by applying a standardized set of questions and data elements to their information management systems. The AADS is one of many standards included in the IM/IT Architecture & Standards Manual that is issued under the authority of the Government Chief Information Officer (GCIO). The Data Standard came into effect in 2007 and applies to all ministries and agencies responsible for the delivery of services and programs designed to improve the social and economic opportunities and outcomes for Aboriginal persons. (2011, personal correspondence, Ministry of Aboriginal Relations and Reconciliation).
Custodian	The Ministry of Aboriginal Relations and Reconciliation (MARR) is the owner of this standard and as such is responsible, along with the Ministry Chief Information Office (CIO), for managing the review and revision process, and for ensuring that the standard is used in future developments..
	Mandate of Custodian: The ministry leads on the provincial government's commitments to bring about long-term reconciliation of Crown and Aboriginal interests through tripartite negotiations of treaties, interim and other workable arrangements with First Nations and Canada. The ministry also leads and supports cross government initiatives to close the socio-economic gap between Aboriginal people and other British Columbians.
Purpose	The purpose of implementing a provincial government data standard for the collection of data specific to Aboriginal persons is to support improved provincial government administrative data. This in turn will support: • culturally appropriate, effective and efficient policy, program and service development; • performance management and measurement; and • socio-economic research, analysis and reporting.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☐ Database includes demographic data
	☐ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other Specify
	☒ Aboriginal ☐ Other Specify
	This is not a database. The Aboriginal Administrative Data Standard defines the data required to provide consistency to Aboriginal identification in provincial government administrative data. For data elements, see section II.
Status & Update	Database status Select One Database update frequency Select One Frequency of Updates: N/A

I. DATABASE – Aboriginal Administrative Data Standard

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): implementation of the standard varies by ministry Month/year of latest available ethno-cultural identifiers:
Level of Detail	1. Select One 2. If Individual Record was selected: Select One 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Depends on the ministry
	Select One
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - This standard should be applied by ministries and agencies responsible for the delivery of services and programs designed to improve the socio-economic outcomes for Aboriginal persons, and ministries and agencies that monitor and measure citizen outcomes. As of November 2011, the following ministries are identified: • Ministry of Education • Ministry of Advanced Education • Ministry of Health • Ministry of Energy and Mines (Housing) • Ministry of Jobs, Tourism and Innovation • Ministry of Social Development • Ministry of Children and Family Development • Ministry of Attorney General • Ministry of Public Safety and Solicitor General
	Select One
Populations	Population groups included in this database – The term Aboriginal as used throughout the Aboriginal Administrative Data Standard is meant to encompass the diversity of Aboriginal persons as broadly defined under the Canadian Constitution Act, 1982, Part II, Section 35(2), as “the Indian, Inuit and Métis peoples of Canada”. For the purposes of Aboriginal identification within British Columbia, the term “First Nation” is often the preferred term in place of “Indian”.
	Population Coverage - % of population targeted by the database that has been captured: This standard should be applied by BC ministries and agencies responsible for the delivery of services and programs designed to improve the socio-economic outcomes for Aboriginal persons, and ministries and agencies that monitor and measure citizen outcomes.
	Alternatively, sample with weights? No. If yes, sample size
Records	Total # of records in database: N/A Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Ministry of Aboriginal Relations and Reconciliation Title of person in support role: Director, FN & Métis Social & Cultural Policy Name: Jan Gottfred Phone: (250) 356-5223 E-mail: Jan.Gottfred@gov.bc.ca
Web site	http://www.gov.bc.ca/arr/

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Below are the Data Elements (bold) and Standard Questions for these Data Elements. The first two data elements are required, the second two data elements are optional: **Aboriginal Identity Indicator** a) Do you identify yourself as an Aboriginal person, that is, First Nations, Métis or Inuit? b) Does this individual identify as an Aboriginal person, that is, First Nations, Métis or Inuit? **Aboriginal Identity Group** a) If you identify yourself as an Aboriginal person, are you: • First Nations? • Métis? • Inuit? b) If this individual identifies as an Aboriginal person is he/she: • First Nations? • Métis? • Inuit? **First Nations Status Indicator** a) Are you registered under the Indian Act of Canada (i.e. a Status Indian)? b) Is this individual registered under the Indian Act of Canada (i.e. a Status Indian)? **First Nations On-Reserve Indicator** a) If you identify yourself as a First Nations person do you live on a reserve? b) If the individual identifies as a First Nations person does he/she live on a reserve? Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached
Question Design	Reason why the above question and/or identifier was chosen: Please describe
	Ethno-cultural identity question(s) has been tested Yes Test report re question design is available Yes Name/citation for test report: The extensive testing Statistics Canada has done for the Census Long Form and Aboriginal Peoples Survey; see citations in the Profiles for Census Long Form and Aboriginal Peoples Survey. • The data identified through this standard is consistent with the Census denominators which allow for National /Provincial/Territorial comparisons. • Statistics Canada has adopted the Census questions as a standard way of identifying Aboriginal groups on other surveys, such as the Aboriginal Peoples' Survey.
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: First time a Canadian jurisdiction has set a cross-governmental standard for First Nations, Inuit and Métis identification: • The adoption of a provincial Aboriginal administrative data standard ensures that information collected is complete, comparable and useful for planning and reporting purposes. • A common definition of the Aboriginal population will enhance inter-ministry coordination across program areas. • Paying for surveys and access to special data sets is expensive. Migration to this standard will entail costs (financial and human resources) but once established will provide an inexpensive source of data that can be used for the above stated purposes. • The data identified through this standard is consistent with the Census denominators which allow for National /Provincial/Territorial comparisons. • Statistics Canada has adopted the Census questions as a standard way of identifying Aboriginal groups on other surveys, such as the Aboriginal Peoples' Survey. This wealth of data can be used to supplement a ministries' administrative data.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated	Yes
	Test /pilot/ evaluation report is available	Yes
	Title/ citation for report: See comments above, under Question Design.	
	MARR will test the efficacy of the new Standard after a reasonable implementation time to allow for field testing, ministry and client feedback.	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Select One 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Any evaluation is specific to each ministry.	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report: No formal evaluation completed to date for cross-government implementation. Ministries have just started data collection and require 4 to 5 years of data collection before they have information for evaluation purposes.	
	Re "data linking": The AADS is specific to the collection of information, not data sharing or linking. However, depending on the ministry and the data sharing and linking agreements in place with other ministries and Aboriginal partners, a consistent standard will support agreements on data linkage. Re "training": There is no cross-government training provided specific to the AADS. Interior Health Authority is providing some, and some ministries provide cultural competency training, but nothing specific to asking the AADS questions. MARR hopes to address this over the next year. Re "awareness/ education materials": MARR has a Q & A question sheet that has been shared with other ministries. However, it is up to each ministry to provide the education and materials.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers	Yes
	Paying for surveys and access to special data sets is expensive. Migration to this standard will entail costs (financial and human resources) but once established will provide an inexpensive source of data that can be used for the above stated purposes.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers	Yes
	Barriers - if any – to ongoing collection of ethno-cultural identifiers: Implementation of the AADS at the different British Columbia ministries varies. Factors include: complexity of changing some IM-IT systems; limited funding to make system changes and to provide training and communications supports; workload pressures at front end of data collection.	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database Legal Authority 1. Canadian Charter of Rights and Freedoms: Section 15 (subsection 1) of the Canadian Charter of Rights and Freedoms reads: Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. Asking an individual to identify as an Aboriginal person is permissible provided there is a legitimate, defensible reason for asking for that information – such as the provision of specially designed programs, policy development, etc. While it is legitimate to ask such a question, it would not be permissible to refuse service(s) on the basis of a person refusing to answer a request for personal information. When asking individuals for personal information, such as their Aboriginal identity, the province must be clear that disclosure is optional and for what purposes the information is being collected. 2. Ministry/Agency Legal Authority: Provincial ministries and their agencies that adopt this standard must comply with their respective legal authority. Freedom of Information and Protection of Privacy (FOIPOP):The Freedom of Information and Protection of Privacy Act [RSBC 1996] CHAPTER 165 makes provision for the collection and protection of personal information. Information requested under this standard must be necessary for “an operating program or activity of the public body” or must be otherwise authorized by the Act. Ministries are each responsible to protect personal information as prescribed under the Act. Section 69 of the Act requires a Ministry to complete a Privacy Impact Assessment to determine whether a new enactment, system, project or program meets the requirements of FOIPPA. A Privacy Impact Assessment has been done for the data standard. In addition, each ministry was/is responsible for its PIA.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Not Applicable If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional): Ministries and Aboriginal organizations came to the table prepared to listen and contribute efforts that included championing the project, providing policy and technical advice, working internally within ministries to raise awareness and begin the process of implementation, and engaging with Aboriginal organizations. Without this level of cross-ministry and Aboriginal investment in the process, this data standard would not exist.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Not Applicable

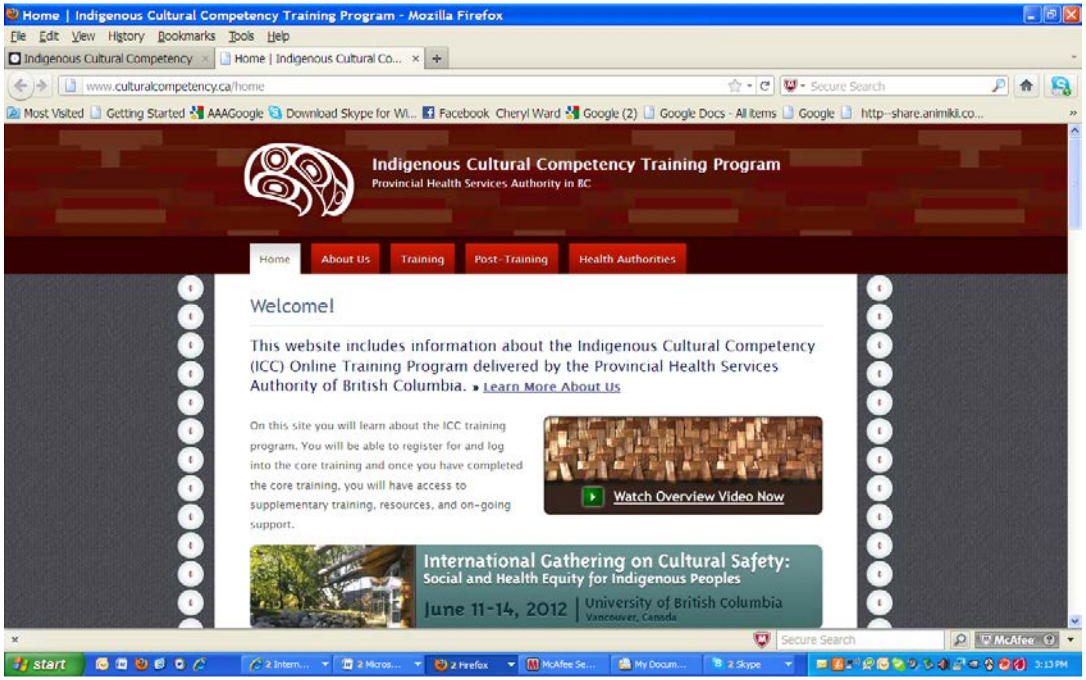
IV. DATA USE & REPORTING	
Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. GOVERNMENT STANDARD FOR ABORIGINAL ADMINISTRATIVE DATA, Ministry of Aboriginal Relations and Reconciliation Intergovernmental and Community Relations, Aboriginal Administrative Data Standard, Version: 1.0, March 22, 2007 2. The AADS has informed the approach Interior Health is taking to their implementation of the Aboriginal Self Identification ASI Pilot Project; cf. corresponding Profile in this Report. 3. At least one ministry is close to using the data collected using the AADS for reporting. [Forthcoming] . Other reports will be prepared once ministries have collected enough data.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: The B.C. ministries - and associated programs and crown agencies - below have implemented the data standard and are gathering data using the standard: 1. B.C. Ministry of Public Safety and Solicitor General: Have fully implemented the AADS - early adopter. 2. B.C. Ministry of Advance Education: All 25 BC post-secondary institutions have implemented the AADS. Two institutions also ask optional AADS questions. 3. Jobs, Tourism and Innovation: Have integrated the AADS into the labour market programs and into the forms used by the Industry Training Authority. 4. Income Assistance - Ministry of Social Development: An early adopter of the Aboriginal self-identity questions, who initiated their own initiative, the Aboriginal Self-identifier Project (ASIP) in 2005. The ASIP employed the same questions and wording as the AADS. Income Assistance undertook a comprehensive consultation process with Aboriginal partners upon initiation of the ASIP project. 5. Child and Family Development - The AADS is being integrated into the plans of MCFD's Integrated Case Management System (ICM). It will take ~ 4 years to phase in ICM. The ICM will allow children to be tracked across program and service areas, and will allow for all data collected by MCFD and delegated Aboriginal agencies to be stored in one place. Some registries already collect Aboriginal self-identity and have since 1996. 6. Ministry of Energy and Mines responsible for the BC Housing Corporation, a crown agency, has fully implemented the AADS.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One While each ministry will have its own process for information sharing, ministries are now guided by BCs “Open Government” initiative announced in the Speech from the Throne on October 3, 2011: " Our government is committed to openness, transparency and engaging with British Columbians. Simply put: we need to be open with the information people have a right to see and open to ideas they have a right to voice. In June, our government launched several initiatives to increase openness and transparency. British Columbia is the first province in Canada to launch an open data website, releasing 2,500 datasets in formats that allow anyone to license and use the information." Cf. http://www.leg.bc.ca/39th4th/4-8-39-4.htm and http://www.data.gov.bc.ca.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes It is the responsibility of each ministry to: 1) Evaluate all business processes and points of contact with clients to determine the changes necessary. In determining if changes are necessary, ministries should identify which opportunities for data collection are consistent with the purposes of implementing this standard, i.e. will collecting data about Aboriginal identity contribute to the purposes for which this standard is intended: a) culturally appropriate, effective and efficient policy, program and service development; b) performance management and measurement; and c) socio-economic research, analysis and reporting.

IV. DATA USE & REPORTING	
	2) Influence their agencies to adopt this standard. Examples of ministry agencies includes but is not limited to the Industry Training Authority; BC Housing Authority; post-secondary institutions; regional health authorities; etc. 3) Clarify to clients/citizens that the collection of their personal information is voluntary and refusal to provide this information will not affect service eligibility. 4) Clarify that personal information will be kept confidential and is protected under the Freedom of Information and Protection of Privacy Act. 5) Ensure Aboriginal identity information is appropriately classified, according to government information classification standards, and the information is handled in accordance with information security standards and the records management practises of government. 6) Work with staff, agencies and Aboriginal stakeholders in implementation of the standard and in ensuring that the client experience in responding to questions is positive. 7) Ensure that all clients have the opportunity to respond to the questions i.e. that there are no assumptions made as to who is Aboriginal or not Aboriginal. 8) Implement this standard in a timely fashion.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

4.1.2 Indigenous Cultural Competency Training Program

A training program designed to improve access to health services and health outcomes for Aboriginal people has trained more than 4,100 people since it was launched 19 months ago. Launched January 2010, The Indigenous Cultural Competency (ICC) Training Program was created in response to the Transformative Change Accord First Nations Health Plan requirement to provide mandated training which will increase cultural competency within health authorities.

ICC training is designed to increase Aboriginal-specific knowledge, enhance individual self-awareness and strengthen skills for non-Aboriginal health care leadership, professionals and service providers of the Provincial Health Services Authority, Ministry of Health and the five regional health authorities. PHSA collaborated with Indigenous and health authority partners on the design, development and implementation of this educational program. Beginning with a provincial "Think Tank" in November, 2008, the curriculum, online training platform and instructional model were developed by March 2009 with input from First Nations, Aboriginal and non-Aboriginal leaders, professionals and scholars, health authority leaders and a team of First Nations, and Métis curriculum writers and technicians.



Welcome!

This website includes information about the Indigenous Cultural Competency (ICC) Online Training Program delivered by the Provincial Health Services Authority of British Columbia. » Learn More About Us

On this site you will learn about the ICC training program. You will be able to register for and log into the core training and once you have completed the core training, you will have access to supplementary training, resources, and on-going support.

International Gathering on Cultural Safety: Social and Health Equity for Indigenous Peoples
June 11-14, 2012 | University of British Columbia
Vancouver, Canada

The self-paced training program is delivered through a facilitated, on-line course consisting of eight modules. Depending on learning style, participants should be able to get through each module in about an hour a week over an eight-week time frame.

Skilled facilitators guide and support each participant as they learn about terminology; diversity; aspects of colonial history such as Indian residential schools and Indian Hospitals, time line of historical events; and contexts for understanding social disparities and inequities. Through interactive activities participants examine culture, stereotyping, and the consequences and legacies of colonization. Participants are also introduced to tools for developing more effective communication and relationship building skills.

The core curriculum is intended as foundational training, and can be supplemented by region- or nation- specific training offered by regional health authorities or Indigenous groups. For example, Fraser Health offers a one-day training program in partnership the Stó:lö Nation where participants spend the day in a big house learning about Stó:lö cultural expectations.

And this is just the beginning for what's possible. The ICC Training Program is in the final stages of developing a pair of additional training modules specifically about mental health and substance misuse.

The program also offers a short additional module titled "Bystander to Ally" which is a curriculum designed to support people who wish to address issues such as stereotyping.

Additionally, there is a non-health focused version of the core ICC course. This was developed in response to requests from allied professions and is marketed toward local municipalities, police, and provincial and national organizations.

The courses are offered tuition free for employees of B.C.'s six health care authorities and the Ministry of Health. For those not employed by a health authority, the tuition is $250, with net proceeds going to support future Indigenous Cultural Competency continuing education activities and conferences.

At the end of the core ICC training, participants will receive a certificate of completion. The program meets the accreditation criteria of The College of Family Physicians of Canada and has been accredited for up to eight Mainpro-C credits and eight Mainpro-M1 Credits.

For more information and to register, please see the Indigenous Cultural Competency (ICC) Training Program website: www.culturalcompetency.ca. Key contact:

Cheryl Ward, Provincial Lead, PHSA Indigenous Cultural Competency Program; Telephone: 250-754-3385; Email: cward@phsa.ca

4.1.3 Interior Health – Aboriginal Self Identification Project

I. DATABASE – Interior Health - Aboriginal Self Identification Project				
Geography	☐ Canada ☒ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☒ Other Interior Health			
Description	The Aboriginal Self Identification (ASI) initiative, which collects data on the Aboriginal identity of Interior Health clients, patients and employees, will assist in efforts to design and deliver more culturally sensitive programs. The ASI project is made up of two components: the employee self-identification program, which started June 24th, 2011 and a four-phase patient/client program. Phase 1, a pilot project with 9 acute care hospitals and 6 health centres in IH East (East Kootenay and Kootenay Boundary) and in collaboration with Ktunaxa First Nation (KFN) and Métis Nation of British Columbia (MNBC), started July 29. The employee ASI will help IH deliver culturally appropriate care by implementing health human resource strategies aimed at encouraging Aboriginal people to consider careers in health care. For the patient ASI, trained registration staff will ask all patients during the registration process to self-identify as Aboriginal or Non-Aboriginal. If patients self-identify as Aboriginal, they will be asked a few more questions including whether or not they want to receive Aboriginal Patient Navigator services.			
Custodian	Interior Health. Data sharing agreements with Ktunaxa First Nation and Métis Nation of British Columbia are under development, and work towards increasing information governance along with increasing investments in First Nations and Métis capacity, subject to limitations of Canadian or British Columbian law.			
	Mandate of Custodian: Ensure publicly funded health services are provided to the people of the Southern Interior.			
Purpose	To develop a better understanding of the diverse needs of Aboriginal people, as patients, clients and employees, and better respond to these needs. Collecting this data supports the Transformative Change Accord (an agreement between the Province, Federal Government and First Nations) and the BC government's commitment to close the social and economic gap between First Nations and other British Columbians. The goal of Aboriginal Self Identification (ASI) is to implement the provincially mandated (2007) Aboriginal Administrative Data Standard (AADS) to ultimately improve the health outcomes and experience of Aboriginal patients.			
	☒ Public Health & Surveillance ☒ screening ☐ immunization ☐ communicable disease ☒ other chronic disease, cancer	☒ Operating a Health Organization or System ☒ funding & reimbursement ☒ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy	☒ Service Delivery ☒ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☒ Aboriginal
	☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☒ On Métis register ☐ Other Specify	☐ Other Specify
	The registration process also captures First Nations Status Number (for validation, and to expedite NIHB) and Métis Nation of BC Citizenship Number (for validation and potential future data linking).			
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency	Frequency of Updates: daily	
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Sept-11	Month/year of latest available ethno-cultural identifiers: Nov-11		

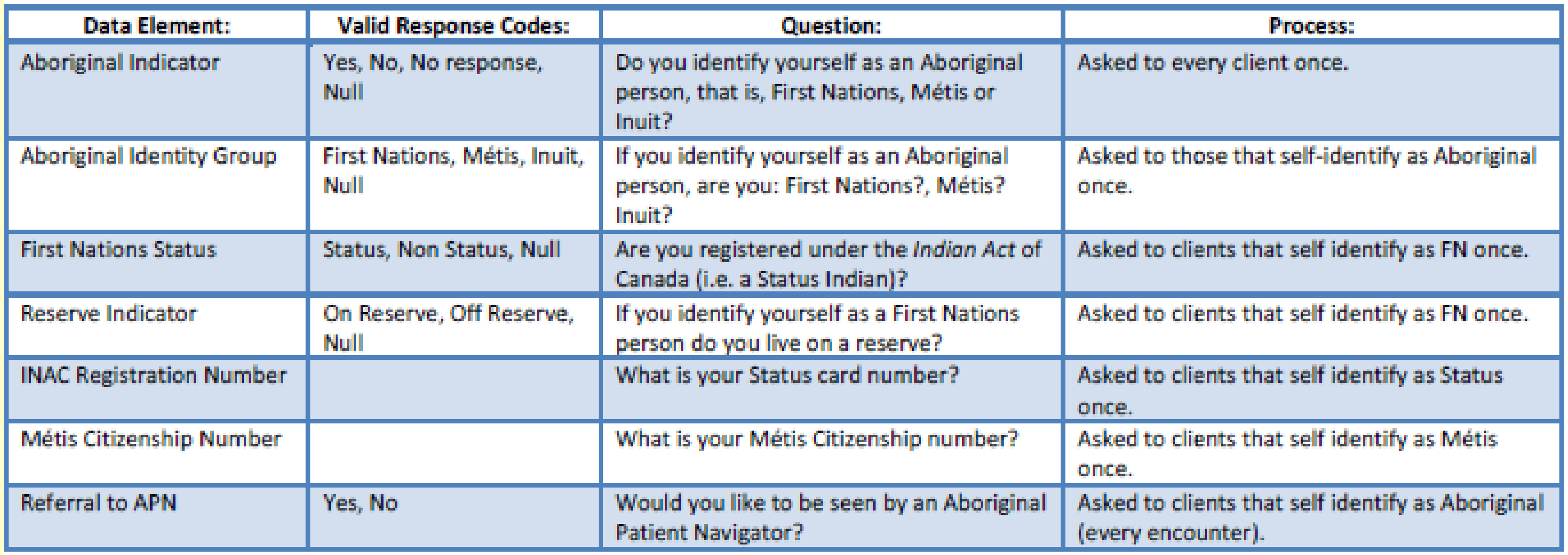
I. DATABASE – Interior Health - Aboriginal Self Identification Project

Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☒ Acute Care ☒ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Interior Health clinicians/ service providers; Interior Health staff with responsibility for specific work force and patient/ client experience goals; Ktunaxa Nation Council and Métis Nation of British Columbia staff (aggregate data)
	Database also used by users external to Custodian
Populations	Population groups included in this database – At this stage: all Interior health employees, and all patients/ clients at 9 acute care hospitals and 6 health centres in East Kootenay and Kootenay Boundary. Longer term rollout target would expand to all patients/ clients of Interior Health across all services.
	Population Coverage - % of population targeted by the database that has been captured: The employee program and patient pilot just started summer 2011, so it is very early days in the roll-out. ~ 2 months into the program, 11% of IH's 17,500 employees have self-identified as anything; ~ 10 employees have refused, and ~ 1.7% of IH clients (140) have self-identified an Aboriginal identity. Aboriginal peoples are 6.7% of the geographic area.
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: Not available yet. Interior Health has ~ 17,500 employees, and serves an area population of 741,709 residents. Interior Health has 55 First Nations communities residing in the Region including: Secwepemc, Southern Carrier, Okanagan, Ktunaxa Kinbasket, Nlakapamux, Stl'atl'imx, and Ts'ilhqotin. In the region there are 44,900 Aboriginal people, which is about 6.3% of the region's population. There are 13 Métis Chartered Communities with a population of 16,200 people, which comprises 36% of the Interior's total Aboriginal population. Annual number of records collected/updated: Interior Health adds records for new employees and patients each year; current employees and patients may update their record at any point in time.
Contact/ Questions	Support Organization Interior Health - Aboriginal Health Title of person in support role: Project Manager, Aboriginal Self-ID Name: Dion Bedard Phone: 250.314.2100 x3778 E-mail: dion.bedard@interiorhealth.ca
Web site	http://www.interiorhealth.ca/health-services.aspx?id=412

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s): All patients are being given the opportunity to self-identify as Aboriginal or non-Aboriginal; no assumptions are being made as to who is Aboriginal and who is not as outlined in the BC Aboriginal Administrative Data Standard. Patients will only be asked once and their answers will become part of their electronic patient record. Registration staff enter registration information directly into the electronic patient record. Patients can change their ASI response at any later time.



Data Element:	Valid Response Codes:	Question:	Process:
Aboriginal Indicator	Yes, No, No response, Null	Do you identify yourself as an Aboriginal person, that is, First Nations, Métis or Inuit?	Asked to every client once.
Aboriginal Identity Group	First Nations, Métis, Inuit, Null	If you identify yourself as an Aboriginal person, are you: First Nations?, Métis? Inuit?	Asked to those that self-identify as Aboriginal once.
First Nations Status	Status, Non Status, Null	Are you registered under the *Indian Act* of Canada (i.e. a Status Indian)?	Asked to clients that self identify as FN once.
Reserve Indicator	On Reserve, Off Reserve, Null	If you identify yourself as a First Nations person do you live on a reserve?	Asked to clients that self identify as FN once.
INAC Registration Number		What is your Status card number?	Asked to clients that self identify as Status once.
Métis Citizenship Number		What is your Métis Citizenship number?	Asked to clients that self identify as Métis once.
Referral to APN	Yes, No	Would you like to be seen by an Aboriginal Patient Navigator?	Asked to clients that self identify as Aboriginal (every encounter).

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier were chosen: Aboriginal organizations have been involved in the development of the ASI questions. The Ministry of Aboriginal Relations and Reconciliation (MARR) also worked with Aboriginal organizations and the First Nations Leadership Council to develop the Data Standard that will be used across ministries for the collection and analysis of information about Aboriginal people.

Ethno-cultural identity question(s) has been tested Select One

Test report re question design is available Select One

Name/citation for test report: The Aboriginal Self Identification (ASI) implements the provincially mandated (2007) Aboriginal Administrative Data Standard (AADS). Cf. Government Standard for Aboriginal Administrative Data, Version 1.0, March 22, 2007, Ministry of Aboriginal Relations and Reconciliation. See also Profile for Aboriginal Administrative Data Standard 1.0. The current pilot is the first phase in a four phase testing and roll-out plan. Evaluation for this first phase will focus on the customer experience during data collection, as well as the practical experiences of registration staff once they have completed their cultural competency training course.

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The ASI project aims to test and expand a comprehensive, integrative approach to the social inequities facing Aboriginal peoples and affecting our entire society, while staying true to the mandate of a health services provider. The approach is comprehensive in that it aims to collect and use employee self-identification data next to patient's data, in the pursuit of both employee and patient quality improvement goals. The approach is integrative in that it aims to build on the provincial work that has been done towards reconciliation, self-

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

governance, and the setting of information standards for and with Aboriginal peoples. The approach stays true to the mandate of a health service employer and provider in that it aims to tie the collection of information directly to initiatives to improve access to quality jobs and quality health service for and with Aboriginal peoples.

Collecting ASI information supports the Transformative Change Accord (an agreement between the Province, Federal Government and Aboriginal Governments), and the BC government's commitment to close the health status gap between Aboriginal people and non-Aboriginal people living in British Columbia. All groups of Aboriginal peoples in Canada experience inequities in health outcomes and a higher rate of chronic disease and injury compared to non-Aboriginal Canadians. Patients who self-identify as Aboriginal will be asked a few more questions including whether or not they want to receive Aboriginal Patient Navigator services. Knowing who our Aboriginal patients are enables IH staff and physicians to deliver more culturally sensitive care and to integrate traditional practices into the patient's care plan. Interior Health's staff and physicians are committed to providing appropriate, culturally competent, high quality care to all patients.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One
Test /pilot/ evaluation report is available Select One
Title/ citation for report: The Pilot Project builds off lessons learned from other similar projects, and is now being conducted for the purpose of a formal evaluation. The identifier questions, which are specified in the Aboriginal Administrative Data Standard, have been adopted from the extensive work and testing Statistics Canada has done for the Census and Aboriginal Peoples Survey.

Data Linkage

Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1.

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

Data Quality

Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
Data quality indicators that are used: Please specify	
Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
Title/citation for test/pilot/quality evaluation report:	

All Registration Staff have taken Indigenous Cultural Competency Training (8-10 hours) in preparation for the July 29th launch date. The ICC program aims to give staff the knowledge, confidence and skills to serve all clients, including clients of Aboriginal descent, in a competent and culturally sensitive way during the registration process. Upon obtaining a Certificate of Completion, staff are provided with access to other support resources. See "Cultural Competency" profile for a full description of this program.

Data Cost

This approach replaces a more costly way to collect ethno-cultural identifiers No
Comments on cost (optional): Interior Health is the first BC Health Authority to ask patients to self-identify. This implementation therefore requires net extra resources for data collection, project management and program evaluation.

Capacity

The custodian plans to keep collecting the ethno-cultural identifiers Yes
Barriers - if any – to ongoing collection of ethno-cultural identifiers: Not known yet; this is partly what the roll-out program will identify.

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database: All information is completely confidential and protected by the Freedom of Information and Protection of Privacy Act. In additions, Interior Health accepts the OCAP principles, subject to limitations of Canadian or British Columbian Law. The information collected by IH is held in a safe and secure environment. Through this pilot project, the information is de-personalized, and then shared with the Ktunaxa Nation Council. This data will be used to identify existing gaps in services and in the development of new programs which will provide improved services for Aboriginal persons living in the Ktunaxa Territory. At no time will anybody other than a patient's medical providers at IHA have access to a patient's private and personal information. In addition, Interior Health is modifying its Research Ethics Board (REB) process, to include Aboriginal representation on the Board. The current REB process already includes an Aboriginal Research Protocol. Aboriginal representation is expected to further strengthen the goal of ensuring that research projects undertaken are consonant with Aboriginal priorities, and viewed through the appropriate cultural lens.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Yes First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☒ Analyst ☒ User for decisions
	Comments on the nature and/or outcome of engagement (optional): In January 2009, Interior Health Authority and the Ktunaxa Nation Council signed a Letter of Understanding (LOU) with the goal of improving patient care to Aboriginal persons receiving services. The Aboriginal Self Identification Initiative is one of the many positive steps that have been taken since the signing, including other initiatives such as Operation Street Angel. The LOU encompasses Health Services for all Aboriginal peoples, including Métis and Inuit, who reside within the Ktunaxa Traditional Territory. The Ktunaxa Nation Council is made up of the communities of St. Mary's, Lower Kootenay, Akisqnuk, and Tobacco Plains. The Ktunaxa Nation Council promotes self-identification to Aboriginal populations living in the IH East region. Interior Health will share de-identified information on Aboriginal patients with Aboriginal Governments for their health care planning purposes. This means that the Aboriginal Governments involved will be using the data from self-identification for analysis and decision making.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Yes | Inuit Land Claims research protocols Select One | Métis requirements Yes

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1. Collecting information on Aboriginal Identity clients and patients will strengthen Interior Health's efforts to design and deliver more culturally sensitive programs and integrate traditional practices into the delivery of health care to First Nations, Inuit and Métis people. 2. Interior Health will share de-identified information with Aboriginal Governments for their health care planning purposes.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: 1. The project enjoys strong clinician and executive support at Ktunaxa Nation Council, including Director Corporate Service, as well as Interior Health, including the CEO, CIO, VP Community Integration, Director Aboriginal Services and Corporate Director Human Resources. 2. The Ktunaxa Nation has its own health plan, and a deliberate, long term strategy to invest in a broad range of determinants of health. Part of KNC's goal is to understand the impact of these investments on health care utilization, which in turn informs their desire for better information. 3. The project partners have agreed on a transparent process for all aspects of the project, including the inevitable challenges. 4. The project builds in time, resources and tools for communication, outreach and training. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

4.1.4 Métis Nation British Columbia Central Registry

I. DATABASE – Métis Nation British Columbia Central Registry				
Geography	☐ Canada ☒ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	The Métis Nation British Columbia (MNBC) Central Registry was introduced in October 2004 and fully implemented in 2005. The provincial citizenship registry is responsible for compiling and maintaining a database of Métis citizens in British Columbia and is based on the process requirements identified as per the Supreme Court decision of Powley. The Powley decision defined not only who the Métis were in Section 35 but affirmed that the specific collective identified has an aboriginal right. The court identified four broad factors in Métis identification: 1. Self-identification 2. Ancestral connection to the historic Métis community 3. Contemporary Métis community acceptance 4. Unique from other Aboriginal peoples			
Custodian	Métis Nation British Columbia			
	Mandate of Custodian: Métis Nation British Columbia develops and enhances opportunities for Métis communities by implementing culturally relevant social and economic programs and services.			
Purpose	The purpose of the Central Registry is to provide an "objectively verifiable process" for Métis identification in the province of British Columbia as governed by the MNBC Citizenship, Senate and Electoral Acts. An individual in possession of an MNBC Provincial Citizenship card can vote and be accepted as a candidate in the Métis Provincial elections, at the Métis Nation Governing Assembly and at the Annual General Meeting. Cardholders may apply for employment training funding and MNBC training initiatives, can register in the education system as a Métis, can apply for bursaries and scholarships and can be defended in court as a Métis citizen. Métis people can apply for bursaries and scholarships without Citizenship as well and while it is more difficult to prove oneself as Métis without citizenship, individuals may apply with a letter from the community they belong to.			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☐ program/service ☐ public policy	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☐ First Nation/North American Indian	☐ Inuit/Inuk	☒ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☒ On Métis register ☐ Other	☐ Other
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates: Ongoing. Members are encouraged to renew their citizenship cards every five years in order to maintain accurate and current statistical and demographic information. Citizens are not removed from the database if they do not renew their card.		

I. DATABASE – Métis Nation British Columbia Central Registry

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 2004 Month/year of latest available ethno-cultural identifiers: Present
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - The MNBC Central Registry is used by staff at the MNBC and has served as a basis for collaboration between the MNBC and external researchers.
	Database also used by users external to Custodian
Populations	Population groups included in this database – Current residents of British Columbia who self-identify as Métis, can provide genealogical evidence of ancestral connection to the historic Métis community, are accepted by the contemporary Métis community and who are unique from other Aboriginal groups. The last criteria is assessed through Aboriginal Affairs and Northern Development Canada by checking that an applicant to the registry is not already registered as belonging to a First Nation.
	Population Coverage - % of population targeted by the database that has been captured: The Central Registry includes approximately 10% of the population of self-identifying Métis residents of British Columbia, as reported by the Statistics Canada Census of the Population.
	Alternatively, sample with weights? No. If yes, sample size
Records	Total # of records in database: 5,920 Annual number of records collected/updated: ~1000
Contact/ Questions	Support Organization Métis Nation British Columbia Title of person in support role: Ministerial Director for Veterans and Health Name: Tanya Davoren Phone: 250-308-7920 E-mail: tdavoren@mnbc.ca
Web site	http://mnbc.ca/citizenship/index.asp

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s):

1. Provide a copy of your family information birth certificate. This document contains name, date, gender, registration date and number, parent's names and birth place.

2. Provide a family information birth certificate for each subsequent generation that you are establishing your Métis ancestry on going back to at least 1901 or earlier. I.e.: parent and grandparent

   An acceptable alternative to a family information birth certificate is a baptismal or christening record, provided the parent's names are recorded on the document. Baptismal or christening records may be obtained from the church where the baptism or christening occurred or from the main Diocese of the Church.

3. A copy of your genealogy ***using the 5-generation pedigree chart provided with the application*** package. ***A pedigree chart must be filled out and submitted for each applicant.*** Include as much information as possible, i.e. birth dates, birthplaces, marriage dates and places, death dates and places. Without these specific details the Central Registry may not be able to verify your genealogy. Always use maiden names for women when completing the chart.

4. A copy (front and back) of one additional form of BC issued photo identification, such as: BC driver's license, BC Identification, or passport.

5. A current color passport photograph, please print your name clearly on the back of the photo.

6. If you are a member of a local chartered British Columbia Métis community, please include a copy of your card, or your community membership number. Please contact your regional registry clerk for a list of chartered communities, or view it online at www.mnbc.ca If you do not yet have this community membership, you may still proceed with your initial application with MNBC.

7. Sign and date the Indian Register Screening form. Please note that even though 15 years is considered an adult for the purposes of the MNBC citizenship card, the legal age of consent is 19 years in BC and if the applicant is under 19 years their Indian Register screening form must be signed by their parent or legal guardian. The following is a list of acceptable identification as per Indian & Northern Affairs Canada (INAC):
   - i. ***Male applicants*** must include ***one*** of the following ***clearly*** copied identification:
      1. Canadian passport
      2. Birth certificate
      3. BC driver's license, copy of front and back of document required.
      4. BC Identification card, copy of front and back of document required.
   - ii. ***Female applicants*** must include the following ***clearly*** copied identification:
      1. Birth certificate and one the following
      2. BC driver's license, copy of front and back of document required.
      3. BC identification card, copy of front and back of document required.
      4. Canadian passport

   **** Please note applicant's are required to contact the appropriate Registry Clerk to obtain an Indian and Northern Affairs Canada (INAC) screening form as a supplement to this application. The INAC form is a duplicate-style form and MNBC is unable to provide it online. Contact information for the Registry Clerks is located on the last page of this document.***

**** All copies of identification must be 100% clear and legible or INAC will reject the form***
**** Applicants are responsible for providing this identification, copied and attached to the INAC form at the time the application is submitted; Registry staff can no longer copy this from applicant files.***

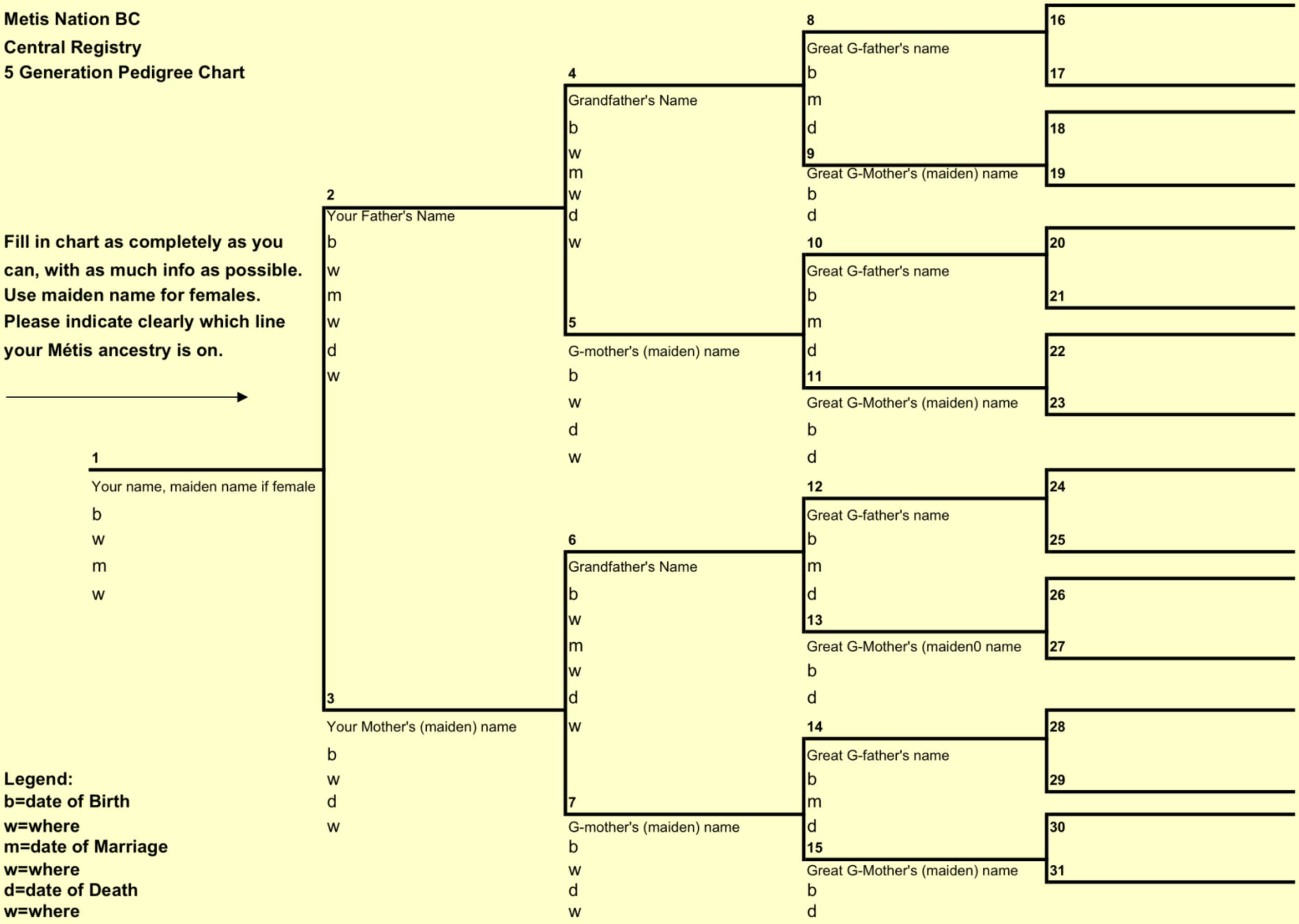
8. Applicants **19 years and older** are required to provide proof of BC residency. This residency must be established for a minimum of ninety (90) consecutive days immediately prior to the date of application. Any of the following documents will be accepted as proof of residency and must include the applicant's name and address:

- Current income support or pay stubs
- Current bills for BC residence (for 3 consecutive months) i.e.: utility/telephone/cable/gas
- Current BC residential property tax bill
- Residential insurance or tenant insurance
- Residential rental or lease agreement
- Registration or grade transcript for post secondary institution

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Metis Nation BC
Central Registry
5 Generation Pedigree Chart

Fill in chart as completely as you can, with as much info as possible. Use maiden name for females. Please indicate clearly which line your Métis ancestry is on.



1
Your name, maiden name if female
b
w
m
w

2
Your Father's Name
b
w
m
w
d
w

3
Your Mother's (maiden) name
b
w
d
w

4
Grandfather's Name
b
w
m
w
d
w

5
G-mother's (maiden) name
b
w
d
w

6
Grandfather's Name
b
w
m
w
d
w

7
G-mother's (maiden) name
b
w
d
w

8
Great G-father's name
b
m
d

9
Great G-Mother's (maiden) name
b
d

10
Great G-father's name
b
m
d

11
Great G-Mother's (maiden) name
b
d

12
Great G-father's name
b
m
d

13
Great G-Mother's (maiden0 name
b
d

14
Great G-father's name
b
m
d

15
Great G-Mother's (maiden) name
b
d

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31

Legend:
b=date of Birth
w=where
m=date of Marriage
w=where
d=date of Death
w=where

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design

Reason why the above question and/or identifier was chosen: In 2003, in R. v. Powley, the Supreme Court of Canada recognized and affirmed the aboriginal rights of the Indian, Inuit and Métis peoples of Canada under Section 35 of the Constitution Act, 1982. The court had already established the test for aboriginal rights in an earlier decision (1996) but it was not until 2003 that the test for rights was adjusted to fit the distinct origins of Métis people. The criteria used to determine eligibility for inclusion in the MNBC Central Registry are based on the four factors determined by the Supreme Court in R. v. Powley (see "Description" above).

Ethno-cultural identity question(s) has been tested No
Test report re question design is available No
Name/citation for test report: Formal testing of the "question" design has not taken place, however, a thorough description of the policies and procedures governing the registry is provided in the following document:

1. Métis Nation British Columbia. Central Registry Policies and Procedures Version 1.0. March 2011. http://mnbc.ca/citizenship/pdf/Central%20Registry%20%20Policy%20and%20Procedures_ver%201.0%20March%202011.pdf

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The Métis have typically been under-represented in health research compared to other Aboriginal groups. This is likely in part due to difficulties associated with identifying Métis people in administrative data sources and the fact that the Métis do not typically live within specific geographic boundaries. The Métis Nation British Columbia Central Registry can act as a cohort for linkage studies. To this end, MNBC signed the Métis Public Health Surveillance Program Information Sharing Agreement with the BC government on September 24, 2011.

The President of Métis Nation British Columbia and the Minister of Health signed an Information Sharing Agreement to match consenting members in the MNBC's Citizenship Central Registry with key Ministry of Health databases, enabling for the first time creation of health-related statistics on the Métis citizens of British Columbia. As a result of the Information Sharing Agreement, the two parties can work towards closing the gap on the quality of life between Métis people and other British Columbians.

Métis Nation British Columbia's Chronic Disease Surveillance Program (CDSP) launched its website on July 22, 2011. The CDSP is a three-way partnership between the MNBC, Public Health Agency of Canada and the BC Provincial Ministry of Health Services. The goal is to increase the available health information on Métis in BC. The CDSP objectives include developing a survey and identifying Métis Citizens in ministerial databases.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No
Test /pilot/ evaluation report is available No
Title/ citation for report: See "Question Design" above.

Data Linkage

Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1.

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

Data Quality

Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Data quality indicators that are used:	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: There are no barriers to the ongoing maintenance of the Registry.	

III. DATA ACCESS

Privacy Constraints	Applications submitted to Regional Registry Clerks (RRC) are stored in secured cabinets and offices, accessible only to the RRC. Citizenship files are stored at the MNBC head office in a secured records room accessible by Registry staff only. Parents or legal guardians of minor children may inquire regarding application status on behalf of their children, however, no other inquiries are permitted. The Central Registry adheres to provincial and federal privacy laws and is subject to federal security and privacy audits.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: MNBC is in the process of undertaking a Chronic Disease Surveillance Project (CDSP). The objective of the CDSP is to establish data linkages between the MNBC Citizenship registry and administrative data held by the BC provincial government, specifically the BC Ministry of Health Services and Vital Statistics. The analysis of this data will provide a valuable resource to Métis communities by making available a valid and reliable measure of Métis health status.
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☒ Collector of data ☒ Custodian ☒ Analyst ☒ User for decisions
	The MNBC registry is controlled, maintained and designed by MNBC and its staff.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:
	First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Yes

IV. DATA USE & REPORTING	
Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: In the fall of 2006, MNBC conducted their first provincial survey. The survey was distributed to households of existing MNBC members and covered a variety of topics, including demographics, education, health, socio-economic indicators, cultural awareness, Métis governance and veterans issues. The findings of that survey can be found in the following document: British Columbia Provincial Health Officer. (2009) Chapter 7: The Métis Population of British Columbia. Pathways to Health and Healing - 2nd Report on the Health and Well-being of Aboriginal People in British Columbia. Provincial Health Officer's Annual Report 2007. Victoria, BC: Ministry of Healthy Living and Sport. MNBC is currently in the process of collecting consent for the Chronic Disease Surveillance Project (see "Secondary Purposes" above), which is likely to yield many analyses/reports/publications and inspire future research endeavours.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: See "Data Products" above.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification No
	Thoughts/advice on factors that would <u>Support</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Rigorous application procedures ensures that every member meets the criteria set forth by the Supreme Court of Canada. <u>Limit</u> the re-application of this ethno-cultural identification approach to other jurisdictions: The application process is very time consuming, both for the applicant and for MNBC.
Additional Comments	There are fees associated with the accrual of supporting documentation from vital statistics agencies. Registry Clerks can provide support if an individual requires assistance with these costs. Furthermore, the Regional Registry Clerks provide support services to Métis applicants in their homes, at community meetings and at many other venues in order to help with the registration process.

4.1.5 Mustimuhw Community Electronic Medical Record

I. DATABASE – Mustimuhw Community Electronic Medical Record	
Geography	☐ Canada ☒ BC ☐ AB ☒ SK ☒ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	Mustimuhw, a community Electronic Medical Record (cEMR) system, is a not-for-profit product owned by Cowichan Tribes. Mustimuhw has been developed specifically to meet the needs of First Nation health care organizations and communities, honoring and recognizing the principles of OCAP. Mustimuhw is currently deployed in over 50 First Nations/sites in three provinces: British Columbia, Manitoba and Saskatchewan.
Custodian	Each community using the Mustimuhw cEMR owns and maintains their own data within the Mustimuhw system.
	Mandate of Custodian: To meet the specific health care needs of First Nations health care organizations and communities by offering an electronic medical record solution built around "integrating community members, health care providers and technology in delivering care with one heart and one mind."
Purpose	The Mustimuhw model is a community-based health information system designed by First Nations for First Nations to incorporate and celebrate the culture of the people using the system. This comprehensive, member-centred electronic health record has been customized to reflect the unique values, missions and goals of each First Nations health centre. Mustimuhw: • Ensures responsibility for decision making is at the community level • Facilitates accessibility of information • Promotes unity in service delivery • Enhances accountability to communities as well as to government.
	☒ Public Health & Surveillance ☒ screening ☒ immunization ☒ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☒ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☒ enrolment/membership ☒ evaluation ☐ equity ☒ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☒ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other
	☐ Aboriginal ☐ Other
	In future, possible identifiers will also include: Inuit, Métis and Other
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: Ongoing
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): APR-03 Month/year of latest available ethno-cultural identifiers: Present
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One

I. DATABASE – Mustimuhw Community Electronic Medical Record

Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☒ Other Band or First Nation
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☒ Home & Community Care ☒ Primary Care ☐ Drugs ☐ Cancer ☒ Diabetes ☐ Renal Dialysis ☒ Immunization ☒ Communicable Disease
Users	Primary users of this database - Health care providers (e.g. nurses), community health directors and members (patients) at each of the participating community health centres use the cEMR. The cEMR is designed to be interactive and to allow patients to view and use printed and on-screen reports of their health status.
	Database also used by users external to Custodian
Populations	Population groups included in this database – Mustimuhw cEMR will include any individual who is accessing health care at, or offered through, a First Nations community Health Centre using Mustimuhw.
	Population Coverage - % of population targeted by the database that has been captured: Mustimuhw captures 100% of individuals accessing health care through the community Health Centre, given that the cEMR is fully integrated into care.
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: Each community holds its own independent database. Number of records is dependent on the community size. Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Mustimuhw, Ts'ewulhtun Health, Cowichan Tribes Title of person in support role: eHealth Engagement Coordinator Name: Tammy Johnston Phone: 250.286.0091 E-mail: tammy.johnston@mustimuhw.com
Web site	http://www.mustimuhw.com

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Below are screens of the Mustimuhw cEMR:

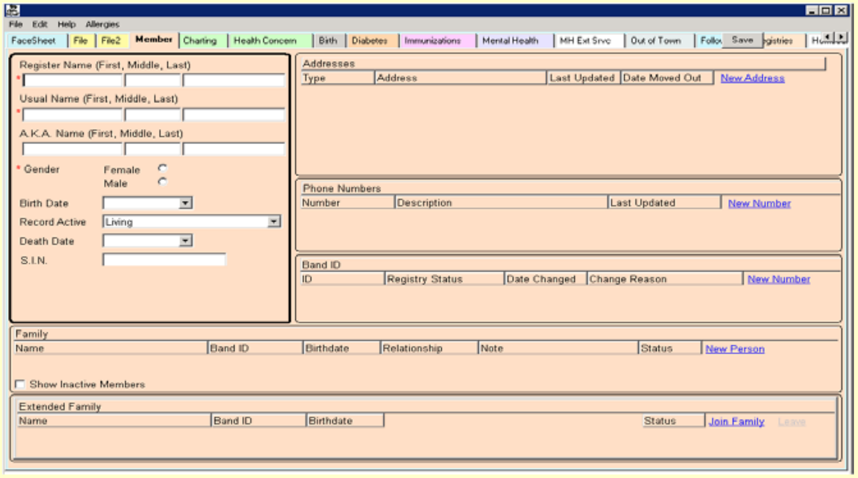
II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Mustimuhw

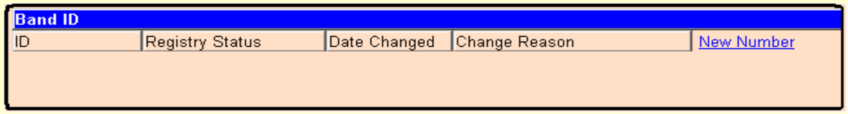
A Community Electronic Medical Record (*c*EMR)

Cowichan Tribes' Mustimuhw Product Management Office

Member Tab – is where the Health Care Provider would gather the demographic information on the member seeking services.

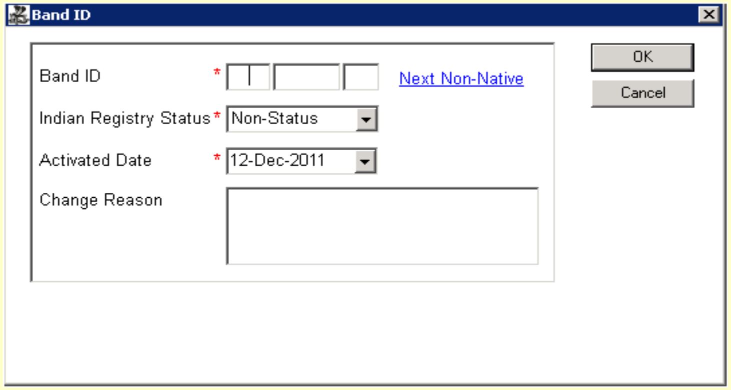


Band ID – is where the status & non-status identifications can be made by clicking **New Number**



II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Which produces the following screen.



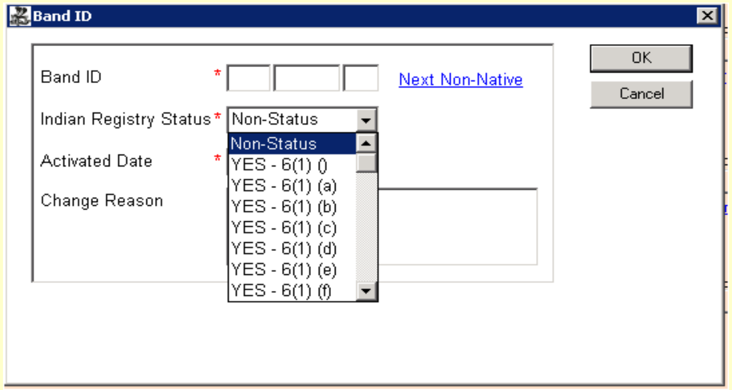
Band ID *

Indian Registry Status * Non-Status

Activated Date * 12-Dec-2011

Change Reason

Clicking the drop down arrow beside the **Indian Registery Status** box will produce a drop down list that currently shows the codes designed by INAC to identify how someone came to have their Status. Future plans are to change these codes to read; Non- Status; Status; Inuit; Metis and Other.



Band ID *

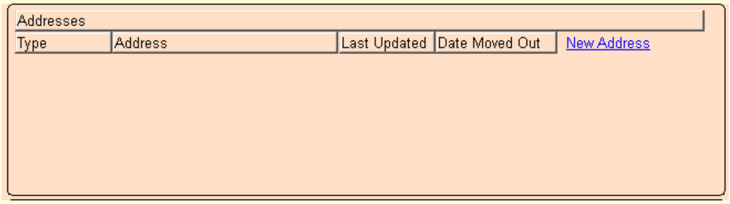
Indian Registry Status * Non-Status

Activated Date *

Change Reason

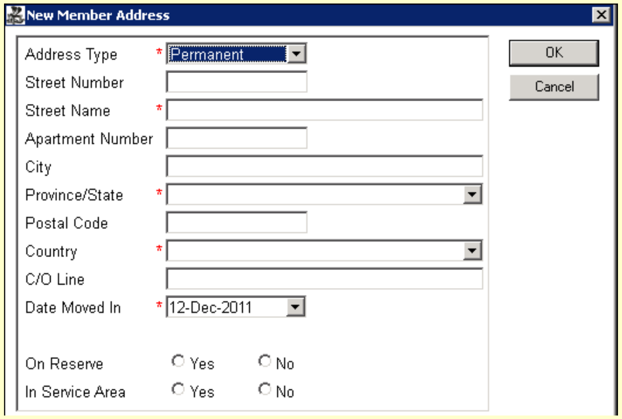
II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Although it does not capture Status or Non-Status information the Address field does capture if a member lives on or off the reserve which may be another important criteria to capture.


Addresses

Type	Address	Last Updated	Date Moved Out	New Address

Note* the **On Reserve** and **In Service Area** are manditory fields to be filled out when completeing an address.


New Member Address

Address Type * Permanent
Street Number
Street Name *
Apartment Number
City
Province/State *
Postal Code
Country *
C/O Line
Date Moved In * 12-Dec-2011

On Reserve ○ Yes ○ No
In Service Area ○ Yes ○ No

Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen: N/A

Ethno-cultural identity question(s) has been tested Select One
Test report re question design is available Select One
Name/citation for test report: N/A

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Ethno-cultural identifiers are not routinely collected at primary and community care centres. One of a number of barriers to collecting this information is the still limited use of EMRs in primary & community care. By putting a community EMR system at the centre of their community health service delivery approach, First Nations who have adopted Mustimuhw are able to connect ethnocultural identifiers to a range of health assessments, outcomes and metrics. In addition, Mustimuhw is designed with the ability to collect comparable data across sites or interface with larger systems such as the Integrated Public Health Information System or Panorama. It is designed to be interoperable more generally, with federal and provincial health information systems. This expands the range of opportunities for ethnocultural specific research and patient navigation, without compromising individual communities' ownership, control, access and possession of their information.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated	No
	Test /pilot/ evaluation report is available	Select One
	Title/ citation for report:	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	No
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes The use of electronic (rather than paper) medical records is time-saving for the staff of the health centres and allows them to spend more time (resources) with patients rather than in administrative tasks.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: For barriers to implementation in other jurisdictions, see "Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions" below.	

III. DATA ACCESS

Privacy Constraints	The primary principle of Mustimuhw is a recognition and acknowledgement that the First Nation is the steward of health information. Health information is held for the benefit of the members of the First Nation and the First Nation commits to protecting the privacy of the individuals and the community's interests. This is in keeping with the principle of OCAP.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: • Communicable disease control: Mustimuhw can be used to track, schedule and follow-up on immunizations, track infectious disease and report infections • Home care: scheduling, timekeeping, charting and reporting • For more examples, see "Data Products" below.
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) | ☒ Collector of data | ☒ Custodian | ☒ Analyst | ☒ User for decisions
	Mustimuhw allows each Nation to incorporate their own pictures, cultural symbols and teachings, supporting the integration of health care into the culture of the community.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Yes | Inuit Land Claims research protocols Not Applicable | Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: Mustimuhw compiles community-level Health Canada reports including: • Immunization coverage reports • Canadian Prenatal Nutrition Program reports • Fetal Alcohol and Maternal Child Health Program reports • Children's Oral Health Initiative screening forms • Medical Patient Transportation forms and reports • Electronic service delivery reporting templates • Home and community care reports …and customizable program reports Further, Mustimuhw has improved the ability for health information to be translated and reported to community leadership. Much of the reporting in Mustimuhw is accomplished by having the software populate Microsoft Excel spreadsheets. This results in easy-to-understand graphs on the front tab, with detailed supporting data on the following tabs. Ts'ewulhtun Health Centre, in British Columbia, reports that the overall graphs are presented to the entire community at Annual General Meetings.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: Following the example above, a community member reported "The graphs presented at the Annual General Meetings have already helped the community make some important decisions on service delivery: One year, the community asked for more home visits by the staff. This became a priority, and a year later, the graphs showed home visits had increased by 15%. However, it also showed that the extra home visiting had come at the cost of group work, which had declined by the same amount. This helped the community understand that within the finite resources available, there are trade-offs. After some discussion, the members decided to go back to building up the group work, because they felt this was more valuable to the community as a whole. For more information see: The Computer World Honors Program Case Study - http://www.cwhonors.org/case_studies/TsewultunHealthCentre.pdf Mustimuhw was implemented fully in three communities and implementation was initiated in three others as part of the Manitoba First Nation "Prevention, Care & Treatment of Foot Ulcers of People living with Diabetes" project. The system facilitated achievement and monitoring of the project's consensus wait times clinical benchmark. The full report, entitled "Patient Wait Time Guarantee Pilot Project" can be found here: "http://www.fnwaittimesguarantee.com/documents.html".
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Mustimuhw is designed with the ability to collect comparable data across sites or interface with larger systems such as the Integrated Public Health Information System (the information system used for reporting case information on all reportable communicable diseases for provincial and national surveillance) or Panorama (a public health surveillance IT application used to manage infectious disease outbreaks). It is designed to be interoperable more generally, with federal and provincial health information systems.
Application of First Nations,	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes The number of users of Mustimuhw is constantly increasing.

IV. DATA USE & REPORTING	
Inuit and/or Métis Identification Approach to Other Jurisdictions	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Mustimuhw was designed from the core OCAP principles promoted by the National Aboriginal Health Organization. It is designed to support a broad range of First Nations Health Centre program needs and business requirements. Mustimuhw supports the continuum of care and enables integration and collaboration amongst Health Centre staff to support interdisciplinary care. It provides foundation level information management and meets reporting requirements to funders and community, while empowering community members in their own care. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Integrating the system into a community may be resource intensive, especially in the initial stages. Information Technology (IT) equipment is required (i.e. laptops, desktops, printers, secure servers, intranet, remote access). With this equipment comes the need for IT support. Additionally, workers must undergo three five-day sessions of training. This investment of time is likely to be recuperated in efficiencies gained by system implementation.
Additional Comments	Mustimuhw focuses on strengths of community members and facilitates the building of capacity in communities. Mustimuhw stands out as a program that involves people in keeping their health records up to date and taking responsibility for their own health.

4.1.6 Tripartite and Bipartite Political Processes

The Profile below describes the history of tripartite and bipartite political processes involving First Nations and Métis peoples in BC.

Synopsis of First Nations Tripartite Political Process in British Columbia:

Transformative Change Accord: On November 25, 2005, the First Nations Leadership Council (FNLC), Province of British Columbia (BC) and Government of Canada (Canada) signed the Transformative Change Accord, committing the parties to: establishing a new relationship based on mutual respect and recognition; reconciling Aboriginal title and rights with those of the Crown; and closing the social and economic gap between First Nations and other British Columbians, in the areas of relationships, education, health, housing and infrastructure, and economic opportunities. The Transformative Change Accord calls upon the Parties to negotiate a 10-year implementation strategy. Previously, in March 2005, the three political organizations in British Columbia (the First Nations Summit, the Union of British Columbia Indian Chiefs and the British Columbia Assembly of First Nations) joined together as the First Nations Leadership Council to speak with one voice to governments.

The Transformative Change Accord: First Nations Health Plan was released on November 27, 2006 by the FNLC and BC. This ten-year Plan includes twenty-nine action items in the following four areas: Governance, Relationships and Accountability; Health Promotion/Disease and Injury Prevention; Health Services; and Performance Tracking. The Parties agreed to , among other things, that (1) the Provincial Health Officer will issue reports on Aboriginal Health in British Columbia every 5 years, with interim updates every two years; and (2) the tripartite data sharing entered into Feb 25, 2002 among B.C., Canada, (as represented by Health Canada's First Nations and Inuit Health Branch) and the First Nations Summit (operating through its then First Nations Chiefs' Health Committee Department), will be renewed to ensure federally and provincial held information on First Nations located in British Columbia ("First Nations in B.C.") is shared.

First Nations Health Plan Memorandum of Understanding: Although Canada was not part of the Transformative Change Accord: First Nations Health Plan, it was interested in negotiating a tripartite plan and demonstrating support for the efforts between First Nations and BC. To this end, a First Nations Health Plan Memorandum of Understanding (MoU) was signed by the FNLC, Canada and BC on November 27, 2006. This MoU includes the same sections and action items as the Transformative Change Accord: First Nations Health Plan, proposes a number of new action items, and required the Parties to develop a Tripartite Health Plan by May 27, 2007.

Tripartite First Nation Health Plan: A new ten-year Tripartite First Nations Health Plan was signed by the FNLC, Canada, and BC on June 11, 2007. This plan builds on the Transformative Change: First Nations Health Plan and includes an agreement by the parties to create and implement a new structure for the governance of First Nations health services in B.C. to improve the health and well-being of First Nations in B.C. through measures that supports the full involvement of First Nations in B.C. in decision-making regarding their health. FNHC, Canada and B.C. have, among other things, agreed in the TFNHP:

1. That their priorities are: governance, relationships and accountability; health promotion and disease and injury prevention; health services and performance tracking;
2. To work together to develop such First Nations data as is desirable and necessary to monitor and report on the health status of First Nations to improve health services First Nations in B.C.;

3. To collaboratively increase the involvement of First Nations in B.C. in decision-making concerning their First Nations Data and health services, through innovations in governance;
4. To cooperate in developing the capacity of First Nations in B.C. in the area of Health governance, to improve First Nations Data access and promote meaningful research for the benefit of First Nations in B.C.;
5. That Indian and Northern Affairs Canada (INAC) and B.C. will enter into a Memorandum of Understanding (information sharing Agreement) to share information to authorize the creation of the First Nations Client File.

First Nations Health Council (FNHC): A key action item referenced in each of these health plans is the establishment of a BC First Nations Health Council, composed of representatives of the First Nations political organizations in BC. This Health Council has been formed, is supported by BC First Nations, and is mandated with: serving as the advocacy voice of BC First Nations in achieving their health priorities and objectives; conducting health-related policy analysis and research; participating in policy and program planning processes related to First Nations health; and providing leadership in the implementation of the First Nations Health Plan Memorandum of Understanding, the Transformative Change Accord; First Nations Health Plan, and the Tripartite First Health Plan. The FNHC incorporated the First Nations Health Society (FNHS).

Tripartite Framework Agreement on First Nation Health Governance: On October 13, 2011, the B.C. First Nations Council and B.C. First Nations Health Society, the Government of British Columbia and the Government of Canada signed a legal agreement that will ensure B.C. First Nations have a major role in the planning and management of health services for First Nations through a new First Nations health governance structure. The British Columbia Tripartite Framework Agreement on First Nation Health Governance paves the way for the federal government to transfer the planning, design, management and delivery of First Nations health programs to a new First Nations Health Authority over the next two years. The First Nations Health Authority will incorporate First Nations' cultural knowledge, beliefs, values and models of healing into the design and delivery of health programs that better meet the needs of First Nations communities. B.C. First Nations will be the first in Canada to take over province wide health service delivery from the federal government and will work closely with the provincial health system to enable it to better meet First Nations health needs and priorities.

Information Policy Initiatives that drive the adoption of data with First Nation identifiers in British Columbia:

BC Government Policy (2007) - The Aboriginal Administrative Data Standard (AADS) was mandated in 2007 to;
Ministry of Education
Ministry of Forests and Range (Housing)
Ministry of Children and Family Development
Ministry of Advanced Education
Ministry of Employment and Income Assistance
Ministry of Attorney General
Ministry of Health
Ministry of Economic Development
Ministry of Public Safety and Solicitor General

It is the responsibility of each Ministry (listed above) to Influence their agencies to adopt this standard in a timely manner. Examples of ministry agencies includes, but is not limited to, the Industry Training Authority, BC Housing Authority, post-secondary institutions, regional health authorities.

The TCA: FNHP (2006) and the TFNHP (2007) identify 29 action items and a further number of action items to be addressed in the Tripartite relationship between the FNHC, Provincial and Federal Governments. This includes 31 actions related to "health actions". The 31 actions include commitments that are dependent on and/or would be greatly enhanced by information with Aboriginal identifiers, such as

- Improve access to maternity services for Aboriginal women

- Increase the number and role of professional and skilled trades First Nations in health professions
- Issue the Provincial Health Officers Report every five years
- Develop indicators to complement the 7 existing indicators in the TCA: FNHP

First Nations in B.C. Tripartite Data Quality and Sharing Agreement: On April 16, 2010, the FNHC, Canada, and BC (represented by the Minister of Healthy Living and Sport and the Minister of Health) signed the First Nations in B.C. Tripartite Data Quality and Sharing Agreement. . The purposes of the Agreement are to:

a) Establish a framework for the Parties to: (i) continually improve the quality and availability of First Nations Data; (ii) facilitate the sharing of First Nation Client File (FNCF) Data in response to research requests approved in accordance with this Agreement; and (iii) to ensure that FNCF Data is appropriately compiled, used and shared by the Parties in accordance with the principles set out in this Agreement and applicable legislation.

b) Create a process for the Parties to develop, promote and act upon initiatives, and facilitate and control access to FNCF Data for the purpose of such initiatives, and to facilitate and control access to FNCF Data for the purpose of such Initiatives or other programs or activities.

c) Commit the Parties to work cooperatively toward the development of systems and protocols empowering First Nations to assume stewardship over the use of First Nation Data, and promote the accessibility of First Nations Data and research.

d) Create new data sets to enable First Nations in B.C. to monitor the health of First Nations and the success of programs and services provided in First Nations Communities in B.C.

e) Recognize First Nations Health Information Governance and ensure that its principles are respected in all circumstances related to the use, collection, and dissemination of First Nations Data and use of the First Nations Client File.

f) Commit the Parties to work together to develop the capacity of First Nations in B.C. to assume eventual, control and management of First Nations Data.

The First Nations Client File (FNCF) means the data file containing the personal information needed to identify First Nations clients, established cooperatively and which the Parties agree is the best method of access to accurate health information about the identifiable majority of First Nations clients residing in British Columbia, who are registered Indians and their entitled children. The First Nations Client File will be created by means of a Memorandum of Understanding (MOU) between the MoHS and Indian and Northern Affairs Canada authorizing and governing disclosure of information contained in the Indian Registry to the MoHS. The First Nations Client File will be used in a process of record matching involving MoHS administrative data on health, or B.C. Vital Statistics Agency data on vital events, or other research data, to produce FNCF Data.

As pointed out in a April 25, 2011 “Memorandum from the Tripartite Data Quality and Sharing Working Group”, a tripartite working group has been established to promote meaningful research, monitor data usage, and to ensure that culturally appropriate and respectful usage of data sets created through the Data Sharing Agreement takes place. The Data Sharing Agreement will help to provide the essential foundation for the development of First Nations research capacity and health information. The signed MoU designates the BC Ministry of Health as the interim data steward, responsible for the file containing information on Registered First Nations (Status Indians) until there is the capacity for a First Nations governance entity to appoint a data steward.

Synopsis of Métis Political Process in British Columbia:

Métis Nation Relationship Accord: In May 2006, the Province and the Métis Nation British Columbia signed the Métis Nation Relationship Accord (MNRA). The MNRA formalized the relationship between the Province and the Métis people of British Columbia, identifying mutual goals to close the gap in quality of life between Métis people and other British Columbians.
The MNRA identified the following objectives

- Strengthen existing relationships based on mutual respect, responsibility and sharing.
- Improve engagement, coordination, information sharing and collaboration.
- Follow through on intentions and commitments of the First Ministers' Meeting on Aboriginal issues as they pertain to Métis people and their aspirations to close the gap in the quality of life between Métis people and other British Columbians.

A preliminary list of subjects for the Métis Nation Relationship Accord process includes:

- Collaborative renewal of the Métis tripartite processes
- Métis identification and data collection
- Health (community, family, individual)
- Housing
- Education (lifelong learning)
- Economic opportunities

Information Policy Initiatives that drive the adoption of data with Métis identifiers in British Columbia:

BC Government Policy (2007) - The Aboriginal Administrative Data Standard (AADS) was mandated in 2007 to;
Ministry of Education
Ministry of Forests and Range (Housing)
Ministry of Children and Family Development
Ministry of Advanced Education
Ministry of Employment and Income Assistance
Ministry of Attorney General
Ministry of Health
Ministry of Economic Development
Ministry of Public Safety and Solicitor General

It is the responsibility of each Ministry (listed above) to Influence their agencies to adopt this standard in a timely manner. Examples of ministry agencies includes, but is not limited to, the Industry Training Authority, BC Housing Authority, post-secondary institutions, regional health authorities.

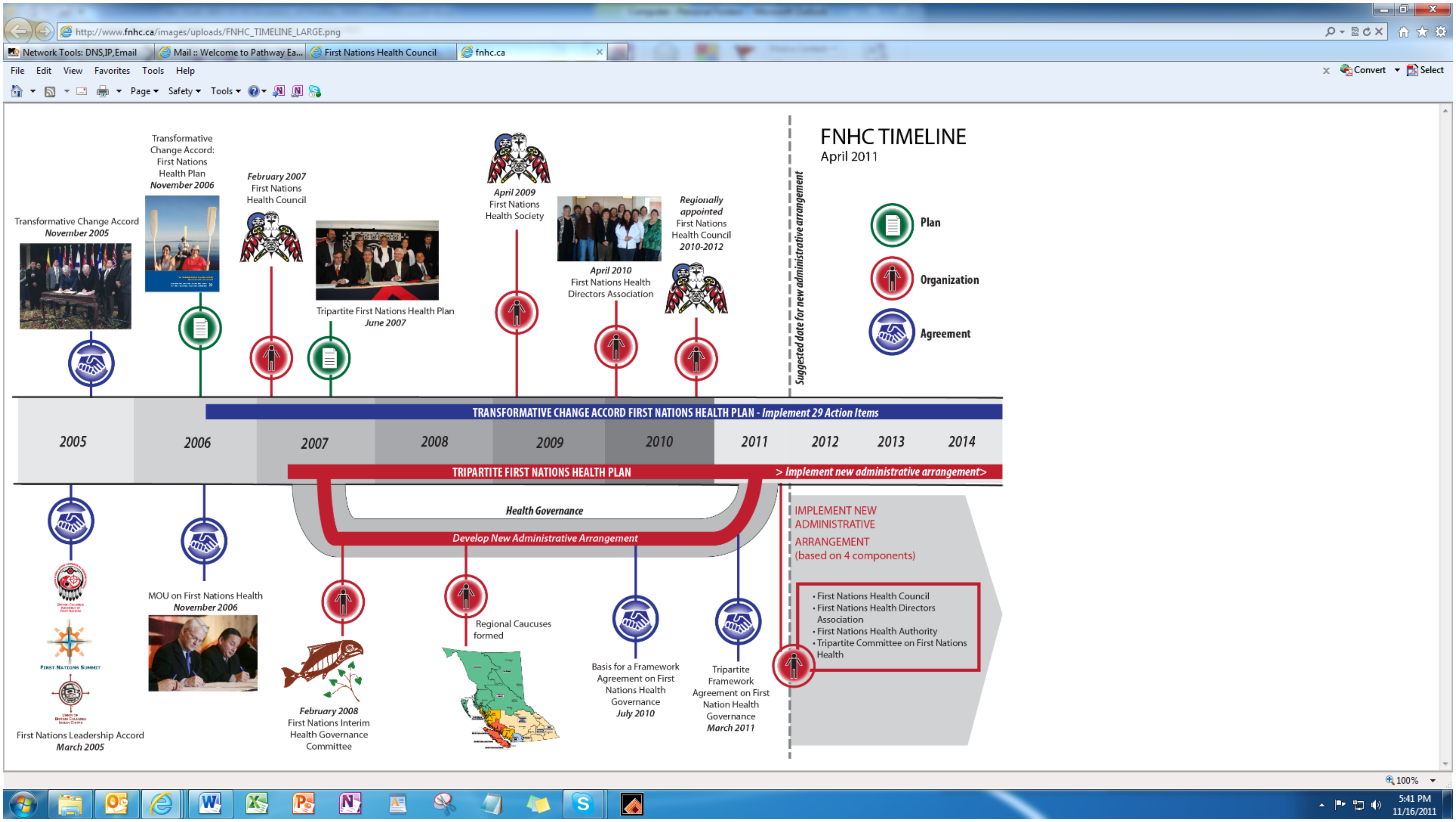
Métis Public Health Surveillance Program Information Sharing Agreement: on September 24, 2011, the President of Métis Nation British Columbia and the Minister of Health signed an Information Sharing Agreement to match consenting members in the MNBC's Citizenship Central

Registry with key Ministry of Health databases, enabling for the first time creation of health related statistics on the Métis Citizens of British Columbia. As a result of the Information Sharing Agreement, the two parties can work towards closing the gap on the quality of life between Métis people and other British Columbians. Over 10 per cent of the self-identified Métis people resident in B.C. have applied and been accepted for citizenship in MNBC.

Métis Nation British Columbia's Chronic Disease Surveillance Program (CDSP) launched its website on July 22, 2011. The CDSP is a three-way partnership between the MNBC, Public Health Agency of Canada and the BC Provincial Ministry of Health Services. The Goal is to increase the available health information on Métis in BC. The CDSP objectives include developing a survey, identifying Métis Citizens in ministerial databases.

Sources:

- Adams E, Martin JD et al, The Tripartite First Nations Health Plan – A Fundamental Change in Governance of Health Services for the First Nations of British Columbia, Canada: Circumpolar Health Supplement 2010; 7, 548-551.
- Mr. Dion Bedard, Project Manager, Aboriginal Self-ID, personal communication
- First Nations Health Council website: www.fnhc.ca, accessed October 13, 2011.
- Health Canada website: http://www.hc-sc.gc.ca/fniah-spnia/services/2011-09_tripartite_plan/index-eng.php, accessed October 13, 2011.
- Kendall PRW, Pathways to health and healing: the Second Report on the Health and Well-being of Aboriginal People in British Columbia. Victoria: Provincial Health Officer's Annual Report; 2007.
- Métis Nation BC website: http://www.mnbc.ca/news/health-information-agreement.asp.
- Ministry of Aboriginal Relations and Reconciliation website: http://www.gov.bc.ca/arr/social/accord.html. Accessed October 13, 2011.


http://www.fnhc.ca/images/uploads/FNHC_TIMELINE_LARGE.png
Network Tools: DNS,IP,Email
Mail :: Welcome to Pathway Ea...
First Nations Health Council
fnhc.ca
File Edit View Favorites Tools Help
Page Safety Tools
Convert Select
FNHC TIMELINE
April 2011
Plan
Organization
Agreement
Transformative Change Accord
November 2005
Transformative Change Accord: First Nations Health Plan
November 2006
February 2007
First Nations Health Council
Tripartite First Nations Health Plan
June 2007
April 2009
First Nations Health Society
April 2010
First Nations Health Directors Association
Regionally appointed First Nations Health Council 2010-2012
Suggested date for new administrative arrangement
TRANSFORMATIVE CHANGE ACCORD FIRST NATIONS HEALTH PLAN - Implement 29 Action Items
2005
2006
2007
2008
2009
2010
2011
2012
2013
2014
TRIPARTITE FIRST NATIONS HEALTH PLAN
> Implement new administrative arrangement>
Health Governance
Develop New Administrative Arrangement
IMPLEMENT NEW ADMINISTRATIVE ARRANGEMENT
(based on 4 components)
• First Nations Health Council
• First Nations Health Directors Association
• First Nations Health Authority
• Tripartite Committee on First Nations Health
First Nations Summit
First Nations Leadership Accord
March 2005
MOU on First Nations Health
November 2006
February 2008
First Nations Interim Health Governance Committee
Regional Caucuses formed
Basis for a Framework Agreement on First Nations Health Governance
July 2010
Tripartite Framework Agreement on First Nation Health Governance
March 2011
100%
5:41 PM
11/16/2011

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.2 SASKATCHEWAN

4.2.1 Métis Nation Saskatchewan Citizenship Registry

I. DATABASE – Métis Nation-Saskatchewan Citizenship Registry	
Geography	☐ Canada ☐ BC ☐ AB ☒ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other
Description	The objective of the Métis Nation – Saskatchewan (MN-S) Citizenship Registry is to register eligible Métis citizens in Saskatchewan through a secure, efficient, standardized, and objectively verifiable process.
Custodian	Métis Nation - Saskatchewan
	Mandate of Custodian: The Métis Nation – Saskatchewan represents the Métis people of Saskatchewan. Its legislative assembly has the authority to enact legislation and resolutions regarding the affairs and conduct of the Métis people of Saskatchewan.
Purpose	The MN-S Registry formalizes and clarifies citizenship requirements, aids in the accurate return of statistical data on Métis citizenship, and provides a basis for improving quality of life for all Métis people in Saskatchewan.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☒ On Métis register ☐ Other
	☐ Aboriginal ☐ Other
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: Ongoing
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): OCT-2009 Month/year of latest available ethno-cultural identifiers: Present
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other
	Postal Code
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer
	☐ Emergency Care ☐ Long Term Care ☐ Diabetes
	☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis
	☐ Rehabilitation ☐ Primary Care ☐ Immunization
	☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease

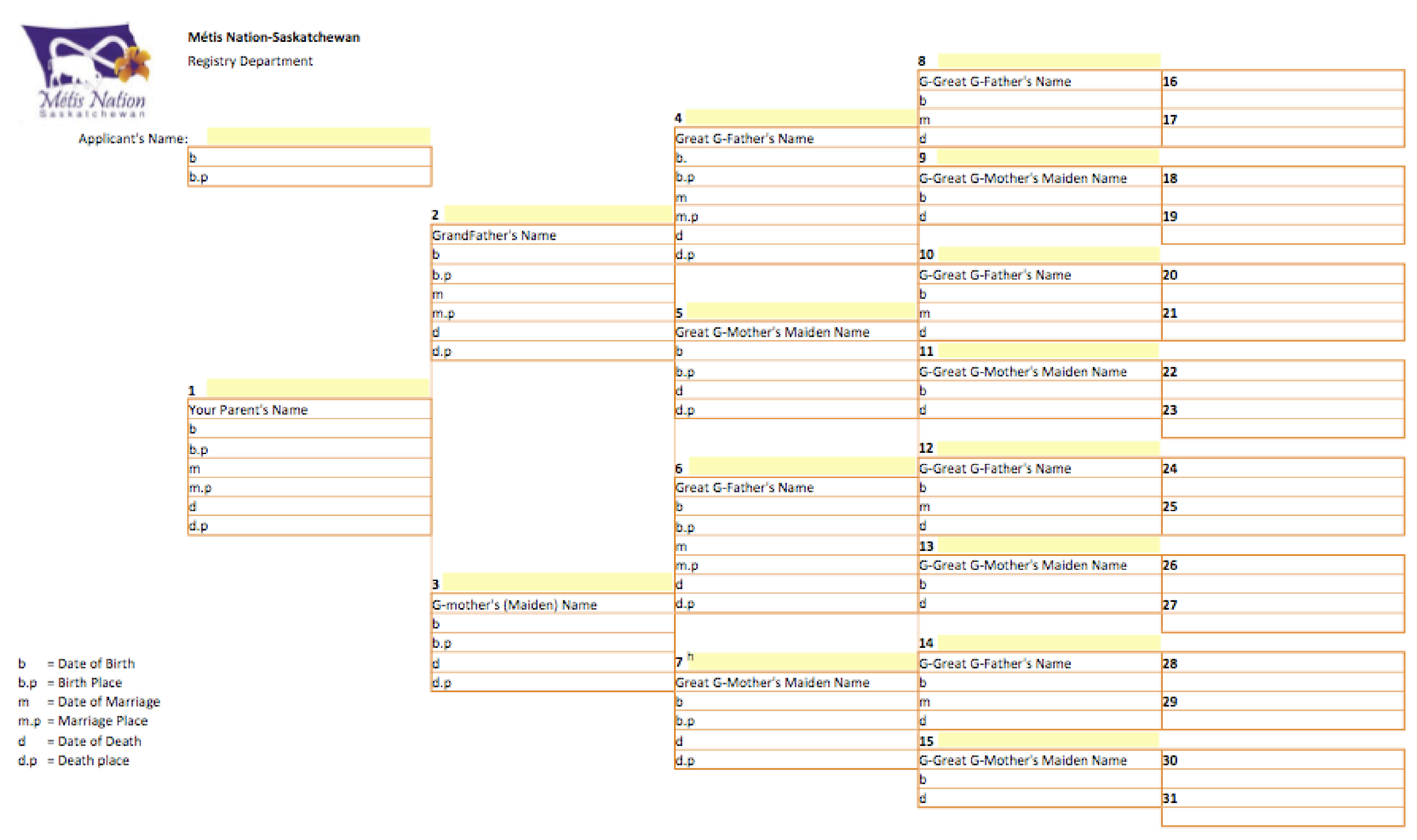
I. DATABASE – Métis Nation-Saskatchewan Citizenship Registry

Users	Primary users of this database - The Métis Nation - Saskatchewan Citizenship Registry is used by staff at the MN-S. Only users internal to Custodian use the database	
Populations	Population groups included in this database – Any person may apply to register with the Métis Nation - Saskatchewan by completing the Citizenship Application Form that proves their connection to a Métis historical ancestor who is recognized as Métis/Half-breed in the historical Métis homeland. Population Coverage - % of population targeted by the database that has been captured: Alternatively, sample with weights? No. If yes, sample size % of population	
Records	Total # of records in database: 1,400 citizenship cards have been administered to MN-S citizens since the introduction of the current registry in 2009, and 4,600 applications are currently being processed. 8,600 records have been archived from a previous iteration of the citizenship registry.	Annual number of records collected/updated: 3,000 to 5,000 new applications are received annually. The MN-S anticipates it will process and distribute 1,100-2,000 citizenship cards annually. This number is largely a function of the capacity at MN-S to process new applications.
Contact/ Questions	Support Organization Métis Nation - Saskatchewan Title of person in support role: Director of Health Name: Tara Turner Phone: 306-343-8391 E-mail: tturner@mn-s.ca	
Web site	http://www.mn-s.ca/main/departments/registry/	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Applicants must provide the following documents: 1) A copy of his or her own genealogical/long form birth certificate 2) The genealogical/long form birth certificate of the parent through whom the applicant is verifying Métis ancestry 3) Pedigree chart going back to at least the year 1901 (see below) 4) Documentation and sources for information included in pedigree chart 5) Current Saskatchewan Health Card, Photo ID

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Métis Nation-Saskatchewan
Registry Department

Applicant's Name:
b
b.p

1
Your Parent's Name
b
b.p
m
m.p
d
d.p

2
GrandFather's Name
b
b.p
m
m.p
d
d.p

3
G-mother's (Maiden) Name
b
b.p
d
d.p

4
Great G-Father's Name
b.
b.p
m
m.p
d
d.p

5
Great G-Mother's Maiden Name
b
b.p
d
d.p

6
Great G-Father's Name
b
b.p
m
m.p
d
d.p

7
Great G-Mother's Maiden Name
b
b.p
d
d.p

8
G-Great G-Father's Name
b
m
d

9
G-Great G-Mother's Maiden Name
b
d

10
G-Great G-Father's Name
b
m
d

11
G-Great G-Mother's Maiden Name
b
d

12
G-Great G-Father's Name
b
m
d

13
G-Great G-Mother's Maiden Name
b
d

14
G-Great G-Father's Name
b
m
d

15
G-Great G-Mother's Maiden Name
b
d

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b = Date of Birth
b.p = Birth Place
m = Date of Marriage
m.p = Marriage Place
d = Date of Death
d.p = Death place

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design

Reason why the above question and/or identifier was chosen: The MN-S defines “Métis” as follows: “a person who self-identifies as Métis, is of historic Métis Nation ancestry, is distinct from other Aboriginal peoples and is accepted by the Métis Nation." All four parts of the Métis Nation –Saskatchewan’s Constitutional Definition must be met in order to receive a MN-S Citizenship Card.

Part 1) Self – identification is demonstrated by signing a declaration on the MN-S Citizenship Application form.

Part 2) Historic Métis Ancestry is demonstrated by:

A) The applicant provides a copy of their long form birth certificate and/or their short form birth certificate with a baptismal certificate and/or a christening record, with parental information.

B) Provide a copy of the long form birth certificate and/or baptismal certificate of the parental with information through which Métis ancestry will be verified. Connecting documents with parental information is required for direct Métis ancestors born after 1901.

C) Provide genealogical information that goes back to the year 1901 using the supplied 5 generation pedigree chart, including as much information and documentation as possible. All applicants must prove their connection to a Métis Historical Ancestor who is recognized as Métis/Half-breed in the historical Métis homeland by completing a family tree that shows the connection from generation to generation.

D) The applicant is required to provide historical records that identify his/her ancestors. These historical records are Métis scrip or census. All genealogical supporting materials are mandatory for the completion of the Citizenship Application Form. The burden of proof of ancestry rests with the applicant.

Part 3) Distinction from other Aboriginal Peoples is accomplished by submission of a completed Indian & Northern Affairs Canada (INAC) Registry consent form. The MN-S Citizenship Registry department has developed a partnership with the local branch office of INAC and sends weekly batches of these consent forms for screening.

Part 4) Acceptance by the Métis Nation is accomplished by belonging to one of the Métis Nation – Saskatchewan Locals or by belonging to the Métis Nation – Saskatchewan

Ethno-cultural identity question(s) has been tested No
Test report re question design is available No
Name/citation for test report:

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The Métis have typically been under-represented in health research compared to other Aboriginal groups. This is likely in part due to difficulties associated with identifying Métis people within administrative data sources and the fact that the Métis do not typically live within specific geographic boundaries. The Métis Nation - Saskatchewan Citizenship Registry can potentially act as a cohort for linkage studies.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No
Test /pilot/ evaluation report is available No
Title/ citation for report:

Data Linkage

Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1.

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used:	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	The information provided in citizenship applications is collected under the authority of the Métis Nation - Saskatchewan Constitution and the Métis Nation - Saskatchewan Citizenship Act. The information collected for the purpose of registration is protected under the provisions of Federal Privacy Act and the Citizenship Act.
	A Privacy Impact Assessment has been done for this database No
	Information has been used for secondary purposes No If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as
	☒ Designer (e.g. of question) ☒ Collector of data ☒ Custodian ☒ Analyst ☒ User for decisions
	The MN-S registry is controlled, maintained and designed by MNA and its staff.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:
	First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Yes

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications:
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions No Examples of evidence-informed decisions:
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification No
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Rigorous application procedure ensures that every member meets the criteria outlined in the definition. (See "Question Design" above) Limit the re-application of this ethno-cultural identification approach to other jurisdictions: It is very time consuming and resource intensive to verify the genealogical evidence. Additionally, potential Métis citizens may lack motivation to compile an application. The Métis Nation of Saskatchewan has a television commercial and brochure to inform potential MN-S citizens of benefits associated with a citizenship card including educational bursaries, scholarships, employment and housing benefits.
Additional Comments	The MN-S assists applicants for citizenship where possible and can provide direction in researching the vital statistic records, census information as well as diocese and parish records. Additionally, the MN-S offers mobile registry intake across the province.

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.3 MANITOBA

4.3.1 Manitoba Métis Federation Membership Registry

I. DATABASE – Manitoba Métis Federation Membership Registry				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☒ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	The Manitoba Métis Federation (MMF) Membership List is a database of Métis citizens in Manitoba. Eligibility for Métis citizenship is based on the National definition of Métis, as agreed upon at the Métis General Assembly in 2003.			
Custodian	Manitoba Métis Federation			
	Mandate of Custodian: The Manitoba Métis Federation is the democratically-elected self-government representative for the Métis Nation's Manitoba Métis community. The MMF promotes and protects the inherent rights of its members. The Manitoba Métis Federation is one of five Governing Members who make up the Métis National Council. The MMF has the following objectives: 1. To promote the history and culture of the Métis people and otherwise to promote the cultural pride of its membership. 2. To promote the education of its members respecting their legal, political, social and other rights. 3. To promote the participation of its members in community, municipal, provincial, federal, Aboriginal, and other organizations. 4. To promote the political, social and economic interests of its members. 5. To provide responsible and accountable governance on behalf of the Manitoba Métis Community using the constitutional authorities delegated by its members.			
Purpose	Membership in the registry determines who receives the rights of members. Rights associated with membership include eligibility for a Harvester card, voting rights in the MMF election, and the right to access programs and services provided by the MMF.			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☒ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☐ First Nation/North American Indian	☐ Inuit/Inuk	☒ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☒ On Métis register ☐ Other Specify	☐ Other Specify
	Comments (Optional)			
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates: Ongoing		
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): The current National Definition of Métis was implemented in September 2008. Prior to 2008, a membership list for the MMF did exist, but the definition used to determine inclusion was different and did not require genealogical proof. By September 2012, only those individuals who meet the 2008 criteria (as described in this document) will be included in the MMF List. This may have some effect on the updating of the Métis Population Database. Month/year of latest available ethno-cultural identifiers: Present			

I. DATABASE – Manitoba Métis Federation Membership Registry

Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - The MMF Membership list is used by the MMF for voting purposes and for delivery of MMF social and economic programs and services. The MMF Membership list has served as a basis for creation of a full provincial Métis database, which is subsequently used for collaboration between the MMF-Health and Wellness Department and external researchers.
	Only users internal to Custodian use the database
Populations	Population groups included in this database – Any Manitoba person who is Métis and who is 18 years of age or older is entitled to membership in the MMF. A Children's Membership may be provided to those 17 years of age or younger.
	Population Coverage - % of population targeted by the database that has been captured: According to the 2006 Census of the Population, approximately 72,000 individuals reported Métis identity in Manitoba. The MMF membership list is approximately 60% of the size of the self-identifying population as measured by the Census. At the time when the MMF Membership list was used as the base to create the Métis Population Data-Base (Dec 31, 2006), all MMF members where 18 years of age or older.
	Alternatively, sample with weights? Select One . If yes, sample size % Of population
Records	Total # of records in database: ~42,500 Manitoba Métis who qualified before and after 2008. Annual number of records collected/updated: MMF is currently in the process of re-registration of all Métis citizens
Contact/ Questions	Support Organization Manitoba Métis Federation Title of person in support role: Membership Registrar Name: Mr. Les Branconnier Phone: (204) 586-8474 E-mail:
Web site	http://www.mmf.mb.ca/index.php?option=com_content&view=article&id=136&Itemid=120

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): To be a member of the MMF one must: 1. Self-identify as Métis 2. Show an ancestral connection to the Historic Métis community: In order to objectively verify the ancestral connection to the Historic Métis Nation, new applicants for membership in the MMF must submit a copy of their own Métis genealogy, or a family member's Métis genealogy and the required supporting evidentiary documents along with their completed application forms and processing fee. The genealogy must be completed by an acceptable recognized genealogical institution. 3. Be accepted by the contemporary Métis community: This is demonstrable by registration in the MMF Central Membership Registry 4. Each application is also screened to ensure that an applicant is not also registered as a member of any Indian Band under the Indian Act, Canada

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

a. You must provide an official genealogy that identifies a Metis Nation Ancestor. This evidence of Historic Métis Nation Ancestry along with supporting evidentiary documents must be completed by an acceptable recognized genealogical institution.

If the genealogy does not have the applicant's name on it, the applicant must provide proof of attached lineage with a copy of a long-form birth certificate or an official baptism certificate listing the parents' names.

b. Government-issued photo identification is required by the institution completing your genealogy as well as a Long Form Birth certificate or Baptismal Certificate with your parent's names.

c. An official genealogy can be obtained from one of the following genealogical institutions:

Métis Culture & Heritage Resource Centre
5th Floor - 63 Albert Street
Telephone: 956-7767
www.metisresourcecentre.mb.ca

St. Boniface Historical Society
340 Provencher Boulevard
Telephone: 233-4888
www.shsb.mb.ca

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen: In September 2002, the Métis Nation adopted a national definition of Métis. This definition is part of the MMF Constitution and defines Métis as follows: "Métis" means a person who self-identifies as Métis, is distinct from other Aboriginal peoples, is of Historic Métis Nation ancestry, and is accepted by the Métis Nation.

"Historic Métis Nation" means the Aboriginal people then known as Métis or Half-breeds who resided in the Historic Métis Nation Homeland.
"Historic Métis Nation Homeland" means the area of land in west central North America used and occupied as the traditional territory of the Métis or Half-breeds as they were then known.
"Métis Nation" means the Aboriginal people descended from the Historic Métis Nation which is now comprised of all Métis Nation citizens and is one of the "aboriginal peoples of Canada" within the meaning of s.35 of the Constitution Act 1982.
"Distinct from other Aboriginal peoples" means distinct for cultural and nationhood purposes.

Ethno-cultural identity question(s) has been tested No
Test report re question design is available No
Name/citation for test report:

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The Métis have typically been under-represented in health research compared

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	to other Aboriginal groups. The MMF Membership list has been used as a cohort of identified Métis citizens and been linked to administrative health data sources in order to provide insight into the health status of Métis people in the province. In June of 2010, the MMF, in collaboration with the Manitoba Centre for Health Policy, produced the first of a series of health-related reports that relied on linkages between administrative data sources. For more information, see "Data Products" below.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No Test /pilot/ evaluation report is available No Title/ citation for report:	
Data Linkage	<u>Potential</u>, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: The MMF Membership Registrar has indicated that salary and training funds for MMF Membership Clerks is very limited. The funding levels should take into consideration that the MMF- Membership List must be accurate for ongoing update requirements for the Métis Population Data-Base.	

III. DATA ACCESS

Privacy Constraints	In applying for membership with the MMF, applicants have entrusted the registry with personal information, and the MMF is committed to protecting this information. The MMF needs to collect a certain amount of personal information from applicants in order to enroll them, keep in touch, and fulfill their mandate and responsibilities. The MMF pledges to use, maintain, and protect personal information responsibly and in accordance with the highest privacy principles and standards, as enshrined in Canadian federal and provincial privacy laws. At registration, the MMF seeks consent for certain data sharing agreements including consent to conduct Métis-specific research on such topics as health, housing, demographics, education, training and employment, such that research does not involve or result in the identification of individuals.
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: In 2010, the MMF in collaboration with the Manitoba Centre for Health Policy (MCHP) published a "Profile of Métis Health Status and Health Care Utilization in Manitoba: A Population-Based Study". This study presents health information for 73,000 Métis people in Manitoba. It is the first of its kind in Canada and provides a comprehensive and scientifically reliable baseline for planning and monitoring trends in health status of Métis over time. The Métis cohort in the report stemmed from the MMF membership list (based on the MMF criteria for membership).
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) | ☒ Collector of data | ☒ Custodian | ☒ Analyst | ☒ User for decisions
	The MMF Membership List is controlled, maintained and designed by MMF and its staff.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Yes

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: The MMF-Health & Wellness Department (MMF-HWD), formed in July 2005, undertakes both qualitative and quantitative (aggregate data analysis) research, report development and knowledge translation. The MMF-HWD's aim is to ensure Métis participation in health planning to inform provincial health policies and programs. For the "Profile of Métis Health Status and Healthcare Utilization in Manitoba", the MMF-HWD researchers and health staff were integral research team members with the MCHP. The MMF-HWD provided Métis context for the study and were extensively trained by the MCHP team in descriptive analysis of aggregate data. In the following reports, the MMF Membership list served as a starting point for establishing the cohort of Manitoba Métis citizens. Further information about the data linkages that were used in the reports are included in the profile of the Métis Population Data-Base. 1. Martens PJ, Bartlett J, Burland E, Prior H, Burchill C, Huq S, Romphf L, Sanguins J, Carter S, Bailly A. Profile of Métis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study. Winnipeg, MB: Manitoba Centre for Health Policy, June 2010. http://mchp-appserv.cpe.umanitoba.ca/deliverablesList.html 2. Bartlett JG, Sanguins J, Carter S, Turner D, Demers A, Kliewer E, Mehta P, Hoeppner N, Musto G, Morgan B. Cancer and related health care utilization in the Manitoba Métis population. Winnipeg, MB: Manitoba Métis Federation. 2011. 3. Bartlett JG, Sanguins J, Carter S, Hoeppner N, Mehta P. Diabetes and related health care utilization in the Manitoba Métis population. Winnipeg, MB: Manitoba Métis Federation. 2010. All new reports will be found on the MMF website: http://health.mmf.mb.ca/index.php?option=com_content&view=article&id=47&Itemid=60
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. The publications listed above have been used to inform research decisions. For example, the "Diabetes and Related Health Care Utilization in the Manitoba Métis Population" report is the result of concerns voiced by Métis for more detail on diabetes than was available in the first Métis population health report in Canada, the "Profile of Métis Health Status and Healthcare Utilization in Manitoba". 2. The findings of these reports will inform policy and programming from the MMF - Health & Wellness Department and the MMF as a whole.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes MMF-HWD provides annual orientation to MMF Region Membership Clerks. This provides the Membership Clerks with a better understanding of how critical their work is to production of useful health information, which in turn stimulates clerical accuracy.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Rigorous application procedures ensure that every member meets the National Definition of Métis. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Very time consuming to verify all the genealogical information. At any given time, there are thousands of pending applications.

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Additional Comments	The collaboration between MMF staff in the Health & Wellness Department and outside researchers has been a positive and productive one. Co-investigators on the reports have published extensively on building indigenous research capacity and have applied these values and practices to building a positive research partnership between the MMF and the MCHP, among others. See, for example: 1. Hall M, Elias B, Martens P, Mignone J (2009) Building Indigenous capacity to meet health needs and combat health disparities: A Manitoba (Canada) experience. International Circumpolar Health Conference, July, Yellowknife, NWT, Canada. The MMF-HWD will soon be in the planning stages of the next post-census Métis Health Status report. Accuracy in the Métis Membership registry is essential to the production of valid health information.

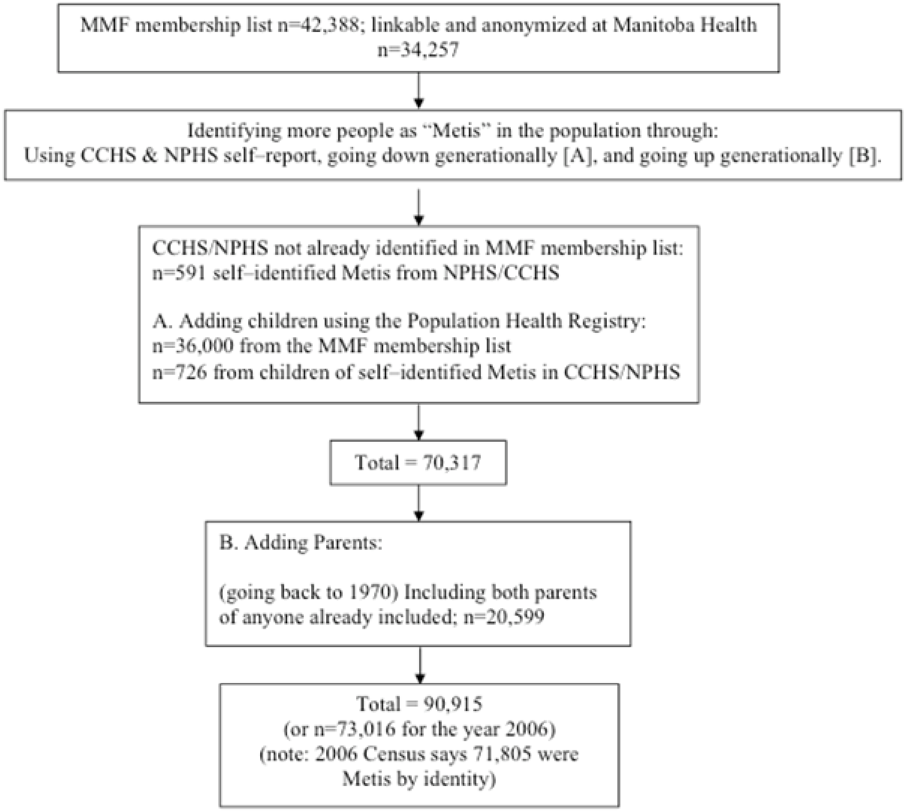
4.3.2 Manitoba Métis Population Database

I. DATABASE – Manitoba Métis Population Database	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☒ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The Manitoba Métis Population Data-Base (MPDB) was developed to identify the Métis population in Manitoba with the intention of linking it to administrative health data for the purposes of population–based studies. The database, produced December 31, 2006, includes individuals identified as Métis from a variety of sources and approximates the Métis population size as reported based on the 2006 Census of the Population.
Custodian	University of Manitoba - Manitoba Centre for Health Policy (MCHP), under a data sharing agreement between the Manitoba Métis Federation (MMF) and the University of Manitoba (UM) houses the MPDB. The MPDB cannot be accessed without the written approval of the MMF, which has created a user-friendly protocol for application for approval.
	Mandate of Custodian: MCHP is a research centre of excellence within the Department of Community Health Sciences, Faculty of Medicine at the University of Manitoba that conducts world class population-based research on health services, population and public health, and the social determinants of health. MCHP develops and maintains the comprehensive provincial population-based de-identified data files in its data repository on behalf of the Province of Manitoba (e.g. health, education, justice, social,) and other registries (e.g. vital statistic-mortality, MPDB) for use by the local, national and international research community. MCHP promotes a collaborative environment to create, disseminate and apply its research. To have access to any database, the MCHP requires approval from the database owner e.g. if a researcher wants to link with education data, approval must be received from Education. MCHP work supports development of policy, programs and services that maintain/ improve Manitobans' health.
Purpose	The Métis Population Database was developed to provide a baseline for further data linkage and research.

☒ Public Health & Surveillance	☐ Operating a Health Organization or System	☒ Research	☒ Service Delivery
☒ screening	☐ funding & reimbursement	☒ population	☐ enrolment/membership
☒ immunization	☐ transactions, e.g. drug dispensing	☐ clinical	☐ evaluation
☒ communicable disease	☐ capacity & utilization planning	☐ program/service	☒ equity
☒ other Chronic disease	☐ performance mgmt. & accountability	☒ public policy	☐ patient navigation

Demographics

☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
☐ First Nation/North American Indian	☐ Inuit/Inuk	☒ Métis	☐ Aboriginal
☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☒ On Métis register ☒ Other Parents and children of Métis (See "Data Sources" below for more details)	☐ Other Specify

I. DATABASE – Manitoba Métis Population Database	
Data Sources	1. Manitoba Métis Federation (MMF) membership list (34,257 members + 36,000 children of members); 2. Canadian Community Health Survey & National Population Health Survey (591 + 726 children of respondents); 3. Parents of individuals identified with sources 1 & 2 (20,599 Métis parents.
	The MPDB began with the MMF membership list (Refer to MMF Membership List Profile). This group was then expanded to include the children and parents of this membership. To ensure inclusion of the maximum number of Métis living in Manitoba whether or not they are members of the MMF, it was decided to look for 'self–identified' Métis from additional sources, specifically the CCHS and the NPHS. For a detailed description of how the database was formed, see "Additional comments" and the flow chart included below.
	

I. DATABASE – Manitoba Métis Population Database

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): December 31, 2006 Month/year of latest available ethno-cultural identifiers: December 31, 2006 An updated Métis Population Data-Base (MPDB) will be created after the Canada Census of 2011. MMF Membership List update is ongoing thus it is possible to update the MPDB in an ongoing manner. To identify trends, it was determined that update of the MPDB would not be required more than every five years (post-Census). Self-identified Métis from the CCHS and NPHS also reported Métis identity in the 2006 Census of the Population.
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☒ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☒ Home & Community Care ☒ Primary Care ☒ Drugs ☒ Cancer ☒ Diabetes ☒ Renal Dialysis ☒ Immunization ☐ Communicable Disease
Users	Primary users of this database - The MPDB was used by researchers at the MCHP and the MMF to produce the first comprehensive Métis health report. Currently the MPDB is being used primarily by the MMF-Health & Wellness Department (MMF-HWD) to produce reports for its Public Health Agency of Canada-funded chronic diseases surveillance program (2010-2015). The MMF-HWD prepares the specifications and gets approval for linkages (e.g. Health, Education, etc.,), then contracts the MCHP to produce the aggregate data, which is transferred to the MMF-HWD for analysis and report writing.
	Database also used by users external to Custodian
Populations	Population groups included in this database – The database includes men and women 18 years and over who belong to and are registered with the Manitoba Métis Federation, men and women who self-identified as Métis in the CCHS or the NPHS, and the children and parents (MMF derived and CCHS/NPHS derived) as identified through the "Repository" family linkages. The "Repository" refers to sets of administrative claims data collectively and formally referred to as the Population Health Research Data Repository, held by the MCHP.
Records	Total number of records in database: 90,915 Manitoba Métis people
Contact/Questions	Support Organization Manitoba Centre for Health Policy Title of person in support role: Adjunct Scientist Name: Judith G Bartlett Phone: (204) 586-8474 E-mail: bartlet0@cc.umanitoba.ca
Web site	http://mchp-appserv.cpe.umanitoba.ca/deliverablesList.html

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: Métis registries in Canada include fewer individuals than self-identify as Métis on the Census. The MPDB is a unique linkage of multiple data sources that expands upon the registry in order to approximate the size of the self-identifying population. The inclusion of self-identifying Métis from surveys, and parents and offspring of registered and self-identifying Métis is an innovative way to increase the number of identified Métis in a cohort and potentially, to have a sample that is more similar to the entire self-identifying Métis population of a province.
Data Quality	The authors considered face validity (i.e. does this way of identifying Métis seem like a valid way?) and concurrent validity (i.e. are the estimates generated based on this method of identifying Métis similar to what we would expect based on results from other methods?) and concluded that this cohort gave reasonable results using such indicators as premature mortality rate. 1. Martens PJ, Bartlett J, Burland E, Prior H, Burchill C, Huq S, Romphf L, Sanguins J, Carter S, Bailly A. Profile of Métis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study. Winnipeg, MB: Manitoba Centre for Health Policy, June 2010. (Page 15)
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes The amalgamation of several pre-existing data sources is cost-efficient since ethno-cultural identifiers have already been assigned to individuals and no new data regarding Métis identification was required.

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Privacy Constraints	MCHP complies with all legislative acts and regulations governing the protection and use of sensitive information. MCHP implements strict policies and procedures to protect the privacy and security of anonymized data used to produce reports and keeps the provincial Health Information Privacy Committee informed of all work undertaken for MB Health. MMF is committed to protection of the MPDB and privacy rights of Métis citizens. This is achieved through the formal ‘data sharing agreement’ between the MMF and MCHP. Each use of the MPDB requires approval at four levels. The process requires approvals from MMF, MCHP, Manitoba Health’s ‘Health Information Privacy Committee’ (which protects all Manitoba citizens’ right to privacy), and the University of Manitoba’s Health Research Ethics Board (the group which evaluates academic ethics).
	A Privacy Impact Assessment has been done for this database Select One
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Yes First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☒ Analyst ☒ User for decisions
	Undertaking this linkage study created a productive MCHP/MMF-HWD joint Research Team and partnership. The first publication from the database was authored jointly by the MMF and the MCHP. For subsequent data linkage studies, the MCHP has been a supportive peer and mentor to the MMF-HWD researchers in production of additional independent peer-reviewed reports (i.e. Diabetes, and upcoming Mental Health and Cardio Vascular Disease reports). The MMF contracts the MCHP to produce the aggregate data, which is transferred securely to the MMF-HWD for analysis and report development. Research linkages with data not held in the MCHP are also produced under a strict data management protocol identifying when and how data is produced,

III. DATA ACCESS

	transferred, and destroyed. The Métis Cancer report, for example, was completed through an MMF contract with CancerCare Manitoba to produce aggregate data runs and mentor the MMF-HWD staff in analysis of cancer rates and trends. Future research will include infectious diseases, a database now held in the MCHP.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Yes

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Martens PJ, Bartlett J, Burland E, Prior H, Burchill C, Huq S, Romphf L, Sanguins J, Carter S, Bailly A. Profile of Métis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study. Winnipeg, MB: Manitoba Centre for Health Policy, June 2010. http://mchp-appserv.cpe.umanitoba.ca/deliverablesList.html 2. Bartlett JG, Sanguins J, Carter S, Turner D, Demers A, Kliewer E, Mehta P, Hoeppner N, Musto G, Morgan B. Cancer and related health care utilization in the Manitoba Métis population. Winnipeg, MB: Manitoba Métis Federation. 2011. 3. Bartlett JG, Sanguins J, Carter S, Hoeppner N, Mehta P. Diabetes and related health care utilization in the Manitoba Métis population. Winnipeg, MB: Manitoba Métis Federation. 2010. All new reports will be found on the MMF website: http://health.mmf.mb.ca/index.php?option=com_content&view=article&id=47&Itemid=60
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. The publications listed above have been used to inform research decisions. For example, the "Diabetes and Related Health Care Utilization in the Manitoba Métis Population" report is the result of concerns voiced by Métis for more detail on diabetes than was available in the first Métis population health report in Canada, the "Profile of Métis Health Status and Healthcare Utilization in Manitoba". 2. The findings of these reports will inform policy and programming within Manitoba's Regional Health Authorities through MMF Knowledge Networks (KNs) that are in place in 9 of 11 Regional Health Authorities (RHA) in Manitoba. KNs are discussion tables led by the MMF and include MMF-Regions and RHA senior program staff who interpret health research outcomes using a local lens. Findings also inform MMF-HWD, the MMF as a whole and at the provincial level.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes The MMF-HWD is committed to knowledge translation. The mission of the MMF-HWD is to 'develop and use knowledge'. This means that for all knowledge that they develop, they have a method to see that it gets used effectively and ethically at many levels in order to influence change in health and social programs delivery. The reports are freely available for download on the MMF-HWD web site.

IV. DATA USE & REPORTING

Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Other Métis Governing Organizations that are members of the Métis National Council are aware of the MPDB and each is moving along differing trajectories to create Métis databases in their provinces. Some have linked their membership list to health files, but whether they can link with the children and parent/grandparents will depend on how their provincial government collects and stores data. It they do not have both individual/ family identifiers, it is not clear how they can proceed. At the same time, for the MPDB creation, once all of the linkages were complete, only ~2% of the MPDB individuals did not have a direct or familial linkage to the MMF membership list. This may be helpful in understanding the quality of Métis membership lists across the country. Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: The MMF and the MCHP signed a data sharing agreement with the MCHP to house the MPDB. With the MMF signature being required as the first approval, this ensures the MPDB remains under full MMF authority i.e., Métis Ownership, Control, Access, and Stewardship (MOCAS). Undertaking this study created a productive MCHP/MMF-HWD joint research team and partnership to produce a 'first of its kind' Métis Atlas in Canada. Co-investigators on the reports have published extensively on building indigenous research capacity and have applied these values and practices to building a positive research partnership between the MMF and MCHP. See, for example: 1. Hall M, Elias B, Martens P, Mignone J (2009) Building Indigenous capacity to meet health needs and combat health disparities: A Manitoba (Canada) experience. International Circumpolar Health Conference, July, Yellowknife, NWT, Canada. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: One might consider that the re-registration (following 2008 definition changes) of the Métis population might be a problem. Such a problem is not a reality since the whole Métis population has been established using multiple data sources. The re-registration of Métis in the Manitoba Métis Federation indicates who is a member of the MMF under the new definition. There will always be individuals who will not want to be a member of the MMF. The MPDB identifies such individuals from alternate sources. One issue that may affect the MMF Membership list accuracy is the lack of sufficient financial resources to update and maintain the list. Data entry staff are on the lower scale of wages in many institutions. High turnover can affect the quality of the Membership list over time.
Additional Comments	Technical description of linkage: The MMF-HWD staff did not have access to MMF members names. The linkage was performed through the mandated MMF Registrar within the Manitoba Health Information Management Branch (HIMB) at Manitoba Health. The HIMB linked the MMF membership list with Personal Health Information Numbers (PHINs). These PHINs were then encrypted (i.e., de–identified with a fictitious number specific to the MCHP Repository). The MMF "list", including the encrypted PHIN along with the MMF Region of membership, was transferred to MCHP from the HIMB. Because the membership lists were mainly comprised of a select group of people who had to be at least 18 years old, the research team worked with the anonymized MMF membership list, other sources of Métis self–identification (the CCHS and NPHS surveys), and the Repository family linkages to create a Métis cohort that approximated the Métis population size in the 2006 Census year.

4.3.3 Registered First Nations & Manitoba Health Insurance Registry Linkage

I.	**DATABASE – Registered First Nations & Manitoba Health Insurance Registry Linkage**
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☒ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The Manitoba Registered First Nations Database refers to the product of a linkage between the Indian Register and the Manitoba Health Insurance Registry (MHIR). Up to the mid-1980s, MHIR did receive annual updates of Registered First Nations (RFN) from the Indian Registry, but that ceased with Bill C-31. Hence, the annual updates in MHIR relied on previous First Nations status to assign this to next generation(s), which was referred to as a "Municipality A" code. This "Municipality A" code identifies the band of origin or associated band rather than a physical location. This was separate from their geographical coding of where they resided. The linked file described here helped overcome problems with large undercounting of the RFN in the MHIR. The linkage was the result of multi-institutional collaboration between the Assembly of Manitoba Chiefs' Health Information Research Committee, Aboriginal Affairs and Northern Development Canada (AANDC), First Nations and Inuit Health Branch, Manitoba Health and the Manitoba Centre for Health Policy (MCHP).
Custodian	Although the data are housed at the Manitoba Centre for Health Policy, the "custodian" of the data (i.e., those who gave permission for its use) was the Assembly of Manitoba Chiefs and AANDC.
	Mandate of Custodian: MCHP is a research centre of excellence within the Department of Community Health Sciences, Faculty of Medicine at the University of Manitoba that conducts world class population-based research on health services, population and public health, and the social determinants of health. MCHP develops and maintains a comprehensive population-based data repository on behalf of the Province of Manitoba for use by the local, national and international research community. MCHP promotes a collaborative environment to create, disseminate and apply its research. The work of MCHP supports the development of policy, programs and services that maintain and improve the health of Manitobans.
Purpose	This database was created as part of a research initiative between MCHP and the Assembly of Manitoba Chiefs (AMC) to produce a "First Nations" atlas of health and the use of health services by First Nations of Manitoba. In order to accomplish this, it was necessary to link federal and provincial health information systems to improve identification. The Atlas was used for the purpose of informing health policies, such as health system integration.
	☒ Public Health & Surveillance ☒ screening ☒ immunization ☐ communicable disease ☐ other
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☐ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy
	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☒ On-reserve ☒ Off-reserve ☒ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other
	☐ Aboriginal ☐ Other

I. DATABASE – Registered First Nations & Manitoba Health Insurance Registry Linkage

	All data are de-identified (i.e. anonymized) prior to being sent to MCHP, through the Health Information Management Branch of Manitoba Health. An encrypted personal health information number, unique to MCHP, is used to link across databases. For the First Nations "flag", this allowed the flag to be assigned to demographic information within the Repository, such as age, sex, area of residence (six-digit postal code), and related health information. The area of residence could be different than the assigned Band number, hence it was presumed that this person was living "off reserve". If the area of residence approximated the Band number geographically, it was assumed that the person was living "on reserve". There are only two First Nations communities in Manitoba where this could be problematic, since a town exists in close proximity to the Band and a person could have the same postal code (i.e. where they pick up mail), but be living either in the First Nations community or the local town.
Data Sources	1. The Indian Register & Status Verification System 2. Manitoba Health Insurance Registry
	1. For more information, see profiles for the Indian Register and Status Verification System 2. The Manitoba Health Insurance Registry is a longitudinal population-based registry maintained by Manitoba Health. The Registry includes all Manitoba residents registered with the Manitoba Health Insurance Plan since 1970.
Availability	Month/year of earliest available ethno-cultural identifiers: JAN-1994 Month/year of latest available ethno-cultural identifiers: DEC-1999
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☒ Other Postal code AND municipality
	Postal Code
Service Domain	☒ Acute Care ☒ Emergency Care ☒ Complex Continuing Care ☒ Rehabilitation ☒ Mental Health/Addictions ☒ Palliative Care ☒ Long Term Care ☒ Home & Community Care ☒ Primary Care ☒ Drugs ☒ Cancer ☒ Diabetes ☒ Renal Dialysis ☒ Immunization ☒ Communicable Disease
Users	Primary users of this database - Researchers who comply with all the requirements (see "Privacy Constraints" below), and who use the Manitoba Centre for Health Policy databases (this would include First Nations researchers and external researchers who meet application criteria). Because of the extensive linkable databases in MCHP, all health care use patterns are able to be studied.
	Database also used by users external to Custodian
Populations	Population groups included in this database – Those RFN who have an affiliation with a Manitoba First Nations band and who were living in Manitoba were eligible to be linked. Manitoba Band members living outside Manitoba or who had out-of-province band affiliation but were residing in Manitoba, were not included.
Records	Total number of records in database: 92,869 RFN were linked to MHIR in 1999. Prior to linkage, 65,526 individuals were identified RFN based on the MHIR.
Contact/ Questions	Support Organization Manitoba Centre for Health Policy, Department of Community Health Sciences, Faculty of Medicine, University of ManitobaTitle of person in support role: Professor in the Faculty of Medicine, Director of the Manitoba Centre for Health Policy Name: Dr. Patricia Martens Phone: 204-789-3791 E-mail: pat_martens@cpe.umanitoba.ca
Web site	http://mchp-appserv.cpe.umanitoba.ca/reference/rfn_report.pdf

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

I. DATABASE – Registered First Nations & Manitoba Health Insurance Registry Linkage

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: The linkage enabled First Nations identifiers in the MHIR to be applied to the collection of data holdings at the MCHP collectively known as the "Population Health Research Data Repository". The Repository is a collection of databases arising from vital statistics, hospital records, medical claims, home care data and surveys, among others. Individual-level data can be analyzed over time and anonymously across databases without requiring names, addresses or other identifying information since every family is assigned a family registration number by the Ministry of Health and every individual is assigned a unique encrypted Personal Health Identification Number (PHIN) by the Ministry of Health.
Data Quality	Linkage of the Indian Register to the MHIR is estimated to have reduced the undercount of Registered Manitoba First Nations individuals from 35% to 5%. Several factors may explain why a 5% undercount persisted; Individuals with a Manitoba Band affiliation living outside of the province could not be linked to the Manitoba Health Registry; First Nations living in Manitoba but affiliated with a non-Manitoba Band would not have been in the file obtained and, finally, births, deaths and surname change after marriage may be under-reported to the Indian Registry.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes The use of pre-existing data greatly reduces the human and financial resources associated with implementing a new ethno-cultural identification system.

III. DATA ACCESS

Privacy Constraints	The principal researcher of the project obtained permission for linkage through Access to Information and the AANDC Privacy Coordinator, through a "Request for Personal Information by Research Body or Researcher, for Research or Statistical Purposes", from Section 8(2)(j) under the federal Privacy Act. For an external researcher to gain access to the holdings at MCHP, a person needs to take an MCHP accreditation course, have a feasibility form sent through MCHP (which estimates feasibility, cost, approximate time frame), obtain appropriate permissions including those from the Assembly of Manitoba Chiefs, the Health Information Privacy Committee, the Health Research Ethics Board of the Faculty of Medicine at University of Manitoba, and for this database, permission from AANDC. A current update of this database is under review, and permission criteria are being considered. The approval process may take 3-4 months, and probably longer for those wishing to access the First Nations identifier. Once a project is approved, the research study data will be analyzed by data analysts within the secure MCHP environment, or be analyzed by the research team itself within the secure MCHP environment.
	A Privacy Impact Assessment has been done for this database Yes
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Yes First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☐ Collector of data ☒ Custodian ☒ Analyst ☒ User for decisions
	For the 1994-1999 database linkage, the First Nations Atlas was done through collaboration with AMC (including representation on the Advisory Group to the Atlas). All research completed using the identifier requires approval through a committee of AMC, and often a designated person from this committee will be engaged in a research project as part of the team. For the ongoing discussions to have a new annual updated identifier in MCHP's Repository, AMC, Manitoba Health and AANDC are undertaking extensive talks to produce a formal agreement. In the meantime, one research scientist (Dr. Brenda Elias) at the Manitoba First Nations Centre for Aboriginal Health Research (MFN-CAHR) has permission for a newer update for a particular set of projects.

III. DATA ACCESS

OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Yes Inuit Land Claims research protocols No Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Martens P, Bond R, Jebamani L, Burchill C, Roos N, Derksen S, Beaulieu M, Steinbach C, MacWilliam L, Walld R, Dik N, Sanderson D, Health Information and Research Committee (AMC), Tanner-Spence M, Leader A, Elias B, O'Neil J. The Health and Health Care Use of Registered First Nations People Living in Manitoba: A Population-Based Study. Winnipeg, MB: Manitoba Centre for Health Policy, March 2002. 2. Elias B, Hall M, Kasper C, Burchill C, Martens P, Kliewer E, Mignone J. Linking the Canadian Indian Registry System to the Manitoba Provincial Health Registry - Lesson learned. International Circumpolar Health Conference, July 2002, Yellowknife, NWT, Canada. 3. Elias B, O'Neil J, Sanderson D. The politics of trust and participation: A case study in developing First Nations and university capacity to build health information systems in a First Nations context. Journal of Aboriginal Health (electronic edition). 2004;1:68-78. For additional examples of data products and reporting, please see "Additional Comments" below.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: This research initiative yielded accurate and timely information that can be used by First Nations communities for better health integration and developing policies. For example, after the First Nations Atlas was produced in 2002, there were extensive discussions between Manitoba First Nations Tribal Councils and various Regional Health Authorities to establish new models of shared healthcare models. The Atlas is constantly referred to in various forums - the 16-fold increase in amputations due to diabetes (and 32-fold increase in one Tribal Council area in the south) compared to all other Manitobans is a frequently cited finding, as well as the finding that the First Nations Tribal Councils in the south showed poorer overall health status (as measured by premature mortality rate, or death before aged 75) compared to those in the north - a finding somewhat non-intuitive to many Manitobans, but very intuitive to the AMC Health Committee representatives. Further study into the discontinuity of diabetes care in southern First Nations communities has been done by Dr. Sharon Bruce (Department of Community Health Sciences, U. of Manitoba). Dr. Bill Leslie has done extensive studies into bone health, using the linked databases.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Many ongoing projects involving collaboration between AMC and MCHP continue to exist. For example, a current project by AMC is using the Repository of data to produce estimates of First Nations infant mortality - this includes researchers from AMC, MCHP and internationally (headed up by Dr. Jane Freemantle, Australia). For additional examples of data products and reporting, please see "Additional Comments" below.
Application of First Nations,	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Comments (optional)

IV. DATA USE & REPORTING

Inuit and/or Métis Identification Approach to Other Jurisdictions	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: The use of pre-existing data greatly reduces the human and financial resources associated with implementing a new ethno-cultural identification system. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: This linkage resulted in the identification of registered First Nations only and therefore excludes non-Status First Nations, Métis and Inuit. However, a more recent initiative between the Manitoba Métis Federation (MMF) and MCHP has resulted in a parallel Métis Atlas, and a "flag" in the Repository for Métis identification. (See the Profile for the Manitoba Métis Population Database for more information).
Additional Comments	The MCHP always works extensively with all stakeholders when going forward with an initiative such as linking databases. All parties must be involved, and respectful relationships must exist between the First Nations, or Métis, or Inuit groups who have a custodial relationship to the data. A Centre such as MCHP does not look upon itself as a custodian. The MCHP holds the data in the Repository in a secured manner but the Assembly of Manitoba Chiefs has "ownership". As an illustration of the positive applications of data linkages such as this and the extent of use for scientific discovery and knowledge translation, a list of publications, conference presentations and reports resulting from the linkage has been included below. Elias B, Kliewer EV, Hall M, Demers AA, Turner D, Martens P, Hong SP, Hart L, Chartrand C, Munro G. The Burden of Cancer Risk in Canada's Indigenous Population: A comparative study of known risks in a Canadian region. International Journal of General Medicine 2011:4 699–709. Martens PJ, Martin B, O'Neil J, MacKinnon M. Distribution of diabetes and adverse outcomes in a Canadian First Nations population: Associations with health care access, socioeconomic and geographical factors. Canadian Journal of Diabetes 2007;31(2):131-139. Lavoie, J. G., Forget, E., Prakash, T., Dahl, M., Martens, P., & O'Neil, J. D. (2010). Have investments in on-reserve health services and initiatives promoting community control improved First Nations' health in Manitoba? Social Science & Medicine (2010), doi:10.1016/j.socscimed.2010.04.037 Martens PJ, Sanderson D, Jebamani LS. Mortality comparisons of First Nations to all other Manitobans: A provincial population-based look at health inequalities by region and gender. Canadian Journal of Public Health 2005:96 (Supplement 1):S33-S38. Martens PJ, Sanderson D, Jebamani LS. Health services use of Manitoba First Nations people: Is it related to underlying need? Canadian Journal of Public Health 2005:96 (Supplement 1):S39-S44. Jebamani LS, Burchill CA, Martens PJ. Using Data Linkage to Identify First Nations Manitobans: Technical, ethical and political issues. Canadian Journal of Public Health 2005:96 (Supplement 1):S28-S32. Martens PJ, Soodeen RM. Health and Health Care in an Aboriginal Population. Epidemiology Supercourse lecture http://www.pitt.edu/~super1/lecture/lec15641/001.htm; 2004 Martens P, Bond R, Jebamani L, Burchill C, Roos N, Derksen S, Beaulieu M, Steinbach C, MacWilliam L, Walld R, Dik N, Sanderson D, Health Information and Research Committee (AMC), Tanner-Spence M, Leader A, Elias B, O'Neil J. The Health and Health Care Use of Registered First Nations People Living in Manitoba: A Population-Based Study. Winnipeg, MB: Manitoba Centre for Health Policy, March 2002. ABSTRACTS: Martens PJ, Health Information Research Committee (Assembly of Manitoba Chiefs), Jebamani L, Bond R, Burchill C, Derksen S. Diabetes, complications, and access to specialist care among Registered First Nations people of Manitoba: population-based comparisons. (oral) Sixth Conference of the Canadian Rural Health Research Society and the First Conference of the Canadian Society for Circumpolar Health: "Bridging the Distance", October 27-29th, 2005.

IV. DATA USE & REPORTING

Quebec City, Quebec.

Martens PJ, Jebamani L. Learning from linkages: Health and healthcare use patterns of Manitoba's Registered First Nations people. (abstract) Health Research in Rural and Remote Canada – Meeting Challenges, Creating Opportunities (Third National Conference). Halifax, Nova Scotia (October 24-26, 2002). Sponsored by the Canadian Rural Health Research Society.

Martens PJ, Jebamani L, Health Information and Research Committee (AMC). The health status of Registered First Nations people: comparisons with all other Manitobans and across Tribal Council areas. (abstract) World Congress of Epidemiology. Montreal, Quebec (August 2002).

Martens PJ, Jebamani L, Health Information and Research Committee (AMC). Comparative rates of health care use by Registered First Nations people and all other Manitobans: Does the system respond to health status? (abstract) World Congress of Epidemiology. Montreal, Quebec (August 2002).

PRESENTATIONS AT CONFERENCES:

Manitoba First Nations RHS Team. "MFN RHS Lessons Learned". Brokenhead First Nation, Manitoba. March 4, 2010. Topic: Martens PJ. MCHP – Who we are and what we do … and how that can contribute to First Nations planning.

Media Interview with the Aboriginal Peoples Television Network. October 3, 2007. Topic: Martens PJ. Diabetes and Amputation rates within First Nations communities – risk factors (Can J Diabetes publication).

Media Interview with Winnipeg Free Press. October 2, 2007. Topic: Martens PJ. Diabetes and Amputation rates within First Nations communities – risk factors (Can J Diabetes publication).

Aboriginal Health & Health Care Course. Winnipeg, MB (October 31, 2006). Topic: Martens PJ. The state of First Nations health: What can population databases show us?

Canadian Rural Health Research Society/Canadian Society for Circumpolar Health. Bridging the Distance. Quebec City, Quebec (October 27-29, 2005).

Topic: Martens PJ. Diabetes, complications and access to specialist care among Registered First Nations people of Manitoba: Population-based comparisons.

Sixth conference of the Canadian Rural Health Research Society, 1st conference of the Canadian Society for Circumpolar Health: Bridging the Distance. Quebec City (Oct 27-29, 2005). Topic: Martens PJ. Diabetes, complications and access to specialist care among Registered First Nations people of Manitoba: population-based comparisons.

Special Chiefs Assembly on Diabetes (Assembly of Manitoba Chiefs). Winnipeg, MB (June 22, 2005). Topic: Martens PJ. The state of First Nations health: What can population databases show us?

Central Regional Health Authority Planning Day with Board of Directors, CEO, MOH and Regional Administrators. Portage La Prairie, MB (April 7-8th, 2005). Topic: Martens PJ, Fransoo R, Burland E, Bowen S. Using data for decision-making, and a workshop on various MCHP/The Need To Know Team reports (First Nations reports, Child Health report, RHA Indicators Atlas, Mental Illness report).

Medical Rehabilitation First Year students. Winnipeg, MB (February 3, 2005). Topic: Martens PJ. The health and health care use of Registered First Nations people living in Manitoba: A population-based study.

Centre for Health Management Research Guest Lecturer, University of Lethbridge. Lethbridge, Alberta (March 18, 2004) Topic: Martens PJ. The Health and Health Care Use of Manitoba's Registered First Nations People: A Population-Based Study Topic: Martens PJ. Coming Full Circle in Primary Prevention: Diabetes and Breastfeeding

Western Regional Training Centre Teleconference Seminar Class (March 5, 2004) Topic: Martens PJ. The First Nations Report.

Medical Rehabilitation second year students. Winnipeg, MB (September 27, 2002). Topic: Martens PJ. "The health of First Nations people in Manitoba."

IV. DATA USE & REPORTING

	The Dean of Medicine's Committee on Aboriginal Professional Issues. Winnipeg, MB (July 3, 2003) Topic: Martens PJ. "MCHP's First Nations' Report: Implications for Professional Education." 1st Annual MCHP & WRHA Health Care Day. Deer Lodge Centre, Winnipeg, MB (April 29, 2003) Topic: Martens PJ. The First Nations Report. CBC North Radio interview. (March 13, 2003) for Yellowknife NWT. Topic: Diabetes, breastfeeding, and First Nations community initiatives. Churchill RHA Board of Directors' meeting. Churchill, MB (February 25, 2003) Topic: Martens PJ. The First Nations report: a discussion of the implications for the people of the Churchill RHA. Deputy Minister of Health's First Nation Technical Working Group. Winnipeg, MB (February 17, 2003) Topic: Martens PJ. The health and health care use of First Nations Manitobans. First Nations and Inuit Health Branch Nurse-in-charge/Physician conference. Winnipeg, MB (January 31, 2003). Topic: Martens PJ. Coming Full Circle in Primary Prevention – diabetes and breastfeeding. First Nations and Inuit Health Branch Diabetes Conference. Winnipeg, MB (November 22, 2002). Topic: Martens PJ. Coming Full Circle in Primary Prevention – diabetes and breastfeeding. Assiniboine and Brandon Regional Health Authorities. Souris, MB (November 20th, 2002) Topic: Martens PJ. The First Nations report: a discussion of the implications for the people of the Assiniboine RHA. This is a community forum at 1:30 pm. Topic: Martens PJ. The health and health care use of Registered First Nations people living in Manitoba. CBC Radio interviews: October 30 and 31st, 2002 Topic: Martens PJ. Factors in early onset Type II diabetes in Manitoba's First Nations children, Interviewed by CBC Saskatoon, and CBC Winnipeg Canadian Rural Health Research Society's third annual conference. "Health Research in Rural and Remote Canada: meeting challenges, creating opportunities." Halifax, NS (October 24-26, 2002). Topic: Martens PJ, Jebamani L. Learning from linkages: Health and healthcare use patterns of Manitoba's Registered First Nations people. Ninth Annual Rural and Northern Health Care Day (MCHP). Winnipeg, Manitoba (October 8, 2002). Topic: Martens PJ. A look at the health of First Nations people of Manitoba. First Nations and Inuit Health Branch Southeast Resource Development Council Diabetes Working Group meeting. Sagkeeng, MB (October 2, 2002), Topic: Martens PJ. An overview of diabetes in Manitoba: from prevalence to prevention. (The First Nations report, the adolescent Type II diabetes research, and the story of Sagkeeng) Medical Rehabilitation second year students. Winnipeg, MB (September 27, 2002). Topic: Martens PJ. "The health of First Nations people in Manitoba." First Nations and Inuit Health Branch Diabetes Working Group meeting. Winnipeg, MB (September 12, 2002). Topic: Martens PJ. An overview of diabetes in Manitoba: from prevalence to prevention. (The First Nations report, the adolescent Type II diabetes research, and the story of Sagkeeng) Central Regional Health Authority Board and Executive Meeting, Portage La Prairie, MB (June 26, 2002). Topic: Martens PJ. The First Nations Report Burntwood Regional Health Authority Board and Executive Meeting, Portage La Prairie, MB (June 26, 2002). Topic: Martens PJ. The First Nations Report Swampy Cree Tribal Council, The Pas, MB (June 19, 2002); and MKO/Independent First Nations North, Thompson (June 20, 2002). Topic: Martens PJ. The First Nations Report CIHR Institute of Population and Public Health: Summer Institute training event entitled "Doing Interdisciplinary Partnered Health Research." Talisman Resort north of Toronto, Ontario (June 9-11, 2002) Topic: mentoring students. Giving a talk about my own research: The Need To Know Team, The First Nations report – collaborative research with policy planners and decision makers

IV. DATA USE & REPORTING	
	MCHP Advisory Board Meeting. Winnipeg, Manitoba (May 10, 2002). Topic: Martens PJ. The Need To Know: update of project. Topic: Martens PJ. The First Nations Report Health Canada, Ottawa, Ontario (April 29, 2002). Topic: Martens PJ. The health and health care use of Registered First Nations people living in Manitoba: a population-based study. Briefings on the Registered First Nations report prior to release: • January 29th, 2002: Minister of Health, Minister of Aboriginal and Northern Affairs briefing • February 8th, 2002: Assembly of Manitoba Chief's: Chiefs' Health Committee • February 6th, 2002: Manitoba Health management executive meeting • February 25th, 2002: Manitoba Health Internal Management • February 27th, 2002: Health Information and Research Committee (AMC) meeting • March 7th, 2002: First Nations and Inuit Health Branch MCHPE Advisory Board: Winnipeg, Manitoba (January 23, 2001) Topic: Martens PJ. Health, health status and health care utilization of Treaty First Nations persons of Manitoba: A POPULIS project. MCHPE 7th Annual Rural and Northern Health Care Day: Winnipeg, Manitoba (October 6, 2000) Topic: CIHR Transition Program CAHR: an update on the progress of the proposal. Topic: The health, health status and health care utilization of Treaty First Nations people of Manitoba: a POPULIS project.

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.4 ONTARIO

4.4.1 Aboriginal Identity Indicator in Cancer Patients - Protocol

I. DATABASE – Aboriginal Identity Indicator in Cancer Patients - Protocol				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☒ Other 2 Regional Cancer Centres in Ontario			
Description	Recognizing the need for alternative methods of collecting cancer information on Ontario's Aboriginal population, Cancer Care Ontario (CCO) and the Ontario Ministry of Health and Long Term Care undertook a pilot project to test the feasibility of collecting Aboriginal race/ethnicity data from people attending Ontario's regional cancer centres. The project included development of a data collection tool and procedures which were then piloted in two cancer centres, one in the urban south and one in the more rural north. Data were collected in the centres between July 1 and September 30, 2009. In October 2009, CCO conducted an in-house evaluation of the pilot. Subsequently, a project evaluation agreement was developed between CCO and the Canadian Partnership Against Cancer (CPAC), to document 'lessons learned' during the pilot, to undertake a formal (i.e., external) evaluation, and to develop a protocol and tool that would support implementation in specialized cancer treatment settings elsewhere. In late 2010, the external evaluation of the pilot was completed. See "Data Products" below for references of the evaluation and protocol documents. The long term value of this project is less for its database, which is relatively small, and more for the extensive documentation of the processes used, the evaluation of these processes, and the resulting "Protocol for Collecting Aboriginal Identity Indicators in Cancer Patients Attending a Specialized Cancer Centre" (2011).			
Custodian	Cancer Care Ontario			
	Mandate of Custodian: Improve the performance of the cancer system by driving quality, accountability and innovation in all cancer-related services.			
Purpose	Assess the burden of cancer on Aboriginal patients attending specialized cancer centres for planning services, setting priorities, monitoring outcomes and managing programs.			
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☒ other cancer	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☒ Aboriginal
	☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☒ On Métis register ☒ Other Métis settlement member	☒ Other open-ended/ self-defined answer (see section II below)
	Comments (Optional)			
Status & Update	Database status Inactive	Database update frequency 1-off Frequency of Updates: N/A		
Availability	Month/year of earliest available ethno-cultural identifiers: July 2009 Month/year of latest available ethno-cultural identifiers: September 2009			
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One			

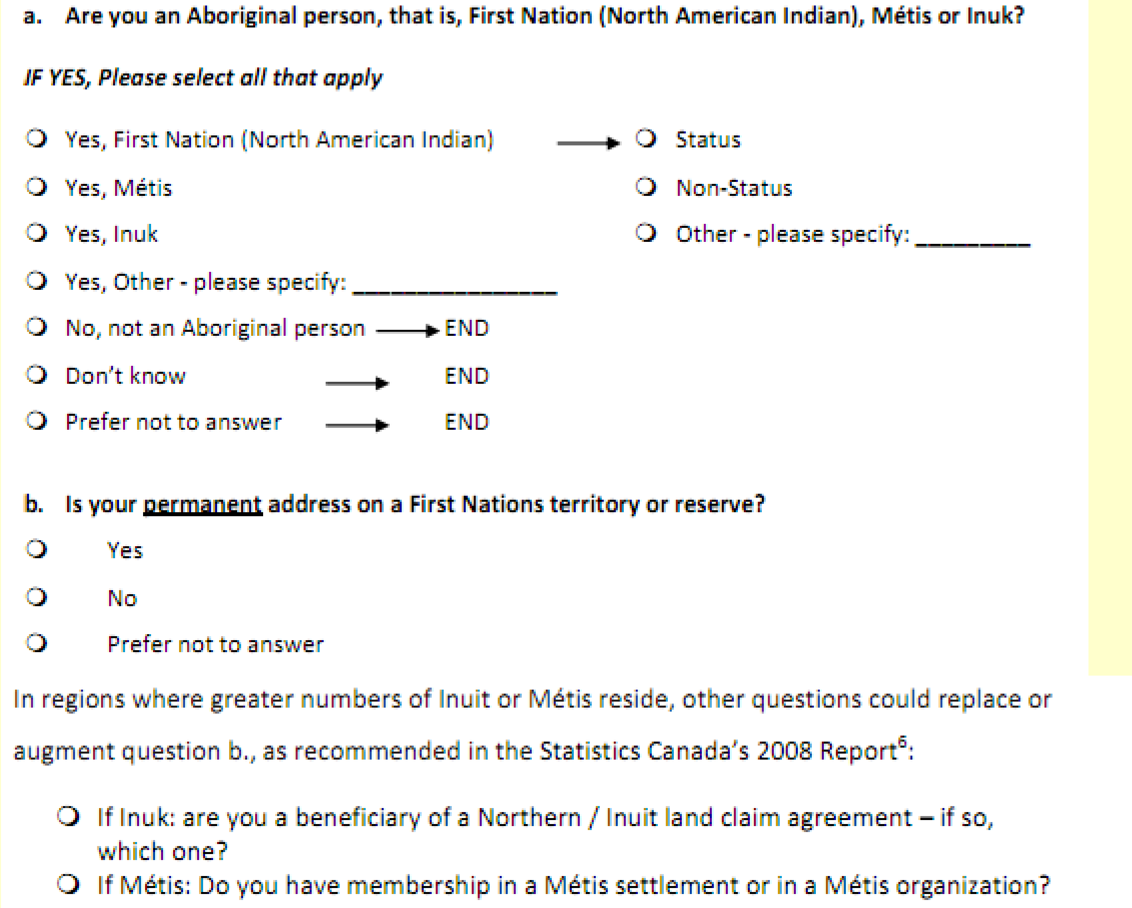
I. DATABASE – Aboriginal Identity Indicator in Cancer Patients - Protocol

Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Clinical and administrative staff, including Aboriginal patient navigator at Regional Cancer Centre, researchers at Cancer Care Ontario.
	Only users internal to Custodian use the database
Populations	Population groups included in this database – Patients attending a specialized cancer centre
	Population Coverage - % of population targeted by the database that has been captured: Ontario Regional Cancer Centres serve ~ 60% of provincial cancer patients, all of whom are captured in the database. In the 3-month pilot, 56% and 34% of patients at the two pilot sites respectively were asked the Aboriginal identity question.
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: Over the 3-month pilot period, the two cancer centres collectively saw 2,567 new cancer patients, 952 (37%) of whom were asked the Aboriginal identity question. Of these, 39 patients (4%) identified as First Nation, Inuit or Métis. Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Cancer Care Ontario Title of person in support role: Senior Scientist and Director, Surveillance Name: Dr. Loraine Marrett Phone: 416-217-1381 E-mail: loraine.marrett@cancercare.on.ca
Web site	http://www.cancerview.ca/portal/server.pt/community/knowledge_circle/536

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): The recommended questions are:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



a. Are you an Aboriginal person, that is, First Nation (North American Indian), Métis or Inuk?

IF YES, Please select all that apply

○ Yes, First Nation (North American Indian) → ○ Status
○ Yes, Métis ○ Non-Status
○ Yes, Inuk ○ Other - please specify: _________
○ Yes, Other - please specify: ________________
○ No, not an Aboriginal person → END
○ Don't know → END
○ Prefer not to answer → END

b. Is your <u>permanent</u> address on a First Nations territory or reserve?

○ Yes
○ No
○ Prefer not to answer

In regions where greater numbers of Inuit or Métis reside, other questions could replace or augment question b., as recommended in the Statistics Canada's 2008 Report[6]:

○ If Inuk: are you a beneficiary of a Northern / Inuit land claim agreement – if so, which one?
○ If Métis: Do you have membership in a Métis settlement or in a Métis organization?

Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen:

1. Questions a. and b. are used by Statistics Canada in the long form Census (2006) and in the Aboriginal Peoples Survey (APS). They are recommended here because they are in widespread use in Canada (so their use in other data collection projects promotes consistency) and have been selected only after consultation, including with national Aboriginal organizations.
2. One must recognize that there is no set of Aboriginal identity questions that is supported by all leaders in the Aboriginal community, and that some indigenous people feel that the term "Aboriginal" is a government artifact and not meaningful.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	3. The 'END' directive in question a. needs to be clear, i.e., it will need to direct the interviewer to the specific section they are to go to next, rather than continuing to question b. above. Testing of these directives will be part of the pre-testing phases. Question b. gathers information that is important in the context of program planning. Being specific about whether this address is permanent is key, given that a substantial number of patients in the remote regions travel away from their homes for extended periods of time for treatment.	
	Ethno-cultural identity question(s) has been tested Yes Test report re question design is available Yes Name/citation for test report: 1. Lidstone-Jones, C. and L. Stewart (2009). Report of Aboriginal Health Data Indicators Pilot. 05160/2008/A. Submitted to the Ministry of Health - Long Term Care. Toronto: Cancer Care Ontario. 2. Cats, H., MacAdam, M., and A. Johnston (2010). Aboriginal Data Indicators Pilot: Project Evaluation – Final Report. Submitted to Cancer Care Ontario. Toronto: Bridge Consulting Group.	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: As the pilot project demonstrated, it is possible to collect Aboriginal identity information through a relatively straightforward intake questionnaire. The internal and external evaluation have validated key elements of this approach, as well as provided a protocol and tools for implementing this approach in other specialized cancer treatment facilities within and outside of Ontario.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Yes Test /pilot/ evaluation report is available Yes Title/ citation for report: see references above.	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Staff participation, client response rate: qualitatively: staff confidence comfort with asking the questions	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes
	Title/citation for test/pilot/quality evaluation report: see references above	
	Comments on quality (optional)	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers No Barriers - if any – to ongoing collection of ethno-cultural identifiers: Time-intensiveness of the work - both for project development/ roll-out and frontline staff training and day-to-day implementation - relative to staffing constraints and staff work load.	

III. DATA ACCESS

Privacy Constraints	As a Health Information Custodian (HIC) under Ontario's Personal Health Information Protection Act (PHIPA), CCO has the authority to collect and use personal health information without patient consent for the purposes of management, evaluation or monitoring of health services. The Privacy Lead at CCO also reviewed the application of OCAP principles in the data collection rationale, methods and storage of data for the pilot project.
	A Privacy Impact Assessment has been done for this database Not Applicable
	Information has been used for secondary purposes No If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Cultural sensitivity, awareness and engagement: It is important for non-Aboriginal people to recognize how cultural backgrounds affect individual perceptions and actions; and how cultural awareness can improve the relationship between people from differing cultural backgrounds. Being culturally sensitive involves an orientation of non-Aboriginal people to the concept of cultural awareness and a greater understanding of the issues and challenges facing Aboriginal people in Canada. Increased awareness of these issues can be accomplished by providing training to those involved in the project. Training materials should include Aboriginal views of health, cancer and treatment; Aboriginal people and health care; and cultural competency in the clinical encounter. Training must be refreshed periodically to recognize new project staff (including at data collection sites) and to reinforce importance. This is expected to enhance ongoing compliance and data quality. An essential aspect of this project is the development of partnerships with local and provincial Aboriginal leaders and groups, as well as cancer patient organizations. Presentations tailored to each community, may be made both early on to garner support and solicit input and direction, as well as later on in the project to provide information.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Yes | Inuit Land Claims research protocols Select One | Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications:
	1. Marrett, L, Kewayosh A, and Stewart L (2011). Protocol for Collecting Aboriginal Identity Indicators in Cancer Patients Attending a Specialized Cancer Centre. Prepared for the Canadian Partnership Against Cancer. Toronto: Cancer Care Ontario. 2. Cats, H., MacAdam, M., and A. Johnston (2010). Aboriginal Data Indicators Pilot: Project Evaluation – Final Report. Submitted to Cancer Care Ontario. Toronto: Bridge Consulting Group. 3. Stewart, L., Lidstone-Jones, C., Marrett, L., Rand, C., McMullen, A., Styres Loft, L., Lynas, C., Nishri, D., and L. Zhou. First Nations, Inuit and Métis Data Indicators Pilot Project. Poster presentation, PHAC workshop. 'Learning from existing methods for conducting Aboriginal chronic disease surveillance in Canada: The way forward'. February 10, 2010, Toronto. 4. Lidstone-Jones, C. and L. Stewart (2009). Report of Aboriginal Health Data Indicators Pilot. 05160/2008/A. Submitted to the Ministry of Health - Long Term Care. Toronto: Cancer Care Ontario.

IV. DATA USE & REPORTING

Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. The work described in this Profile is part of a broader discussion between CCO, the Regional Cancer Centres and First Nations, Inuit and Métis groups at the provincial and regional/ local level about the role and value of better data for Aboriginal cancer control in the province. This, in turn, has led to the incorporation of detailed strategies for a) research and surveillance, and b) aboriginal knowledge transfer and exchange in the new Aboriginal Cancer Strategy (ACS II). These strategies are being reviewed with the above stakeholders in Fall 2011, and are expected to be finalized in early 2012.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Comments on communication approach used and response (optional): Cancer Care Ontario has a dedicated Aboriginal Cancer Program with resources at the provincial as well as regional levels. These provincial and regional resources are leading the sharing of information/research relevant to First Nations, Inuit and Métis groups, as well as joint planning for the implications on program development and service delivery.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: There are several essential steps to successful collection of data on Aboriginal race/ethnicity, and these have been outlined in the reports detailed under "Data Products". These recognize the overarching importance of: 1) A strong project governance and accountability structure; 2) Cultural sensitivity, awareness and engagement; 3) A strong underlying survey methods framework (QDET – questionnaire development, evaluation and testing); and 4) Strong communications plan Limit the re-application of this ethno-cultural identification approach to other jurisdictions: While the steps to implementing a successful data collection protocol are generic, specifics may need to be altered to fit with the procedures and needs at data collection sites and local Aboriginal conventions (e.g., terminology) and concerns, and to take account of updated thinking about specific tools (e.g., ways of asking questions). It is strongly recommended that the project be approached initially as a pilot to enable procedures and tools to be thoroughly worked out in the local setting.
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

4.4.2 Better Outcomes Registry & Network (BORN)

I. DATABASE – Better Outcomes Registry and Network (BORN) Ontario	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	BORN Ontario is a registry under Public Health Information Protection Act (PHIPA) in Ontario and is the repository for maternal child information in Ontario. Data held by BORN is collected from multiple health information sources including laboratories providing prenatal and newborn screening, midwifery practices and hospitals for prenatal, labour, birth and early newborn information. BORN is adding other data sources as they become available.
Custodian	BORN at The Children's Hospital of Eastern Ontario (CHEO)
	Mandate of Custodian: To build and manage the maternal/child registry; to build a source of accurate and timely maternal-infant information for facilitating and improving the provision of health care to pregnant women and children in Ontario; and for analysis of maternal-newborn data to support decision making by health care providers and planners.
Purpose	With a vision of providing the knowledge needed for the best possible beginnings for lifelong health, the mission of BORN is to: • Facilitate and improve care for mothers, children and youth by linking information and providers to address care gaps spanning the spectrum from normal to high acuity and rare conditions • Be an authoritative source of accurate, trusted and timely information to monitor, evaluate and plan for the best possible beginnings for life-long health • Provide scientific and technical leadership for Ontario's maternal, child and youth health system through the support of research and innovation • Mobilize information and expertise to optimize care and contribute to a high-performing healthcare system, improving the lives of individual mothers and children
	☒ Public Health & Surveillance ☒ screening ☐ immunization ☐ communicable disease ☒ other Maternal/child
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other Specify
	☒ Aboriginal ☐ Other
	BORN recognizes the importance of Aboriginal identifiers, however the Registry is currently in transition, and BORN is still establishing stakeholder partnerships and is seeking appropriate approvals for the collection of Aboriginal identifiers at this time. When the new BORN system goes live in January 2012, Aboriginal identity questions will not be collected as part of the BORN system. Once agreements have been reached with the appropriate stakeholders, however, BORN is constructed so that this field can easily be added to the existing system.

I. DATABASE – Better Outcomes Registry and Network (BORN) Ontario

	In the previous version of the BORN system, the aboriginal identity variable came from the Niday Perinatal database. Maternal aboriginal identity was recorded by the health care provider by means of an electronic form containing multiple patient and care-related factors. Potential response categories to the question "Aboriginal?" were: (1) Unknown (2) Not applicable (3) First Nations (4) Métis (5) Inuit. When the new system goes live, the following variable is present, but hidden until stakeholder engagement is complete (and is subject to change, depending on feedback): Is the mother of this child an Aboriginal person, that is, First Nations, Inuit or Métis? (Mark all that apply) a) No b) Yes, First Nations person registered under the Indian Act of Canada living on-reserve c) Yes, First Nations person registered under the Indian Act of Canada living off-reserve d) Yes, First Nations/Indian person not registered under the Indian Act of Canada e) Yes, Inuit f) Yes, Métis
Data Sources	Data included in BORN is collected from a number of sources including: – Prenatal screening – Pregnancy, labour, birth and early newborn care (normal and complex, from hospital and midwifery practices) – Newborn screening
	The personal health information collected includes health insurance numbers, demographic information and clinical information about fetuses, newborn babies, children, and their mothers, including pregnancy history, medical history, and a summary of the care provided during pregnancy, labour, birth and the newborn period.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 2004 Month/year of latest available ethno-cultural identifiers: Dec 2011
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other
	Postal Code
Service Domain	☒ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☒ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease

I. DATABASE – Better Outcomes Registry and Network (BORN) Ontario	
Users	Primary users of this database - BORN discloses personal health information to health information users when facilitating access to care and treatment for mothers, babies and children, for example to ensure appropriate screening is offered in a meaningful timeframe. BORN also discloses personal health information to prescribed entities for the management, evaluation, monitoring or planning for the health system and to researchers for research purposes. These users may include founding members of BORN (i.e. Ontario Maternal Multiple Marker Screening, Fetal Alert Network, Ontario Midwifery Program, Niday Perinatal Database and Ontario Newborn Screening), researchers, health care providers, midwives, and health administrators (i.e. program and patient care managers).
	Database also used by users external to Custodian
Populations	Population groups included in this database – All maternal-newborn pairs in Ontario; a subset of pregnancies which did not result in birth are also included.
Records	Total number of records in database: BORN will capture approximately 140,000 births per year.
Contact/ Questions	Support Organization BORN - Better Outcomes Registry & Network Title of person in support role: Scientific Manager Name: Ann Sprague Phone: 613-737-8579 E-mail: asprague@ottawahospital.on.ca
Web site	http://www.bornontario.ca/

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE	
Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: In a 2009 review of perinatal databases in Canada, only two of six systems collected any ethnocultural identifiers, one of which was the Niday Perinatal Database in Ontario (one of the source databases to the original BORN). For further information, refer to 1. Massey KA, Magee LA, Dale S, Claydon J, Morris T, von Dadelszen P. A current landscape of provincial perinatal data collection in Canada. J Obstet Gynaecol Can. 2009;31(3):236-46.
Data Quality	The aboriginal identifier data element has historically not been well completed. The Ontario Perinatal Surveillance System Report 2008 reported that 2.6% of women giving birth in Ontario from April 2006 to March 2007 were Aboriginal. Of the demographics reported, this variable had the highest rate of non-completion with 56% of records missing data, compared to, for example, 11% missing smoking status, or 15% missing pre-existing maternal health issues.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No However, the creation of the integrated BORN database will support more efficient collection of ethnocultural identifiers. For example, identifiers collected at an early stage of pregnancy can be carried forward and applied to data collected at a later maternal-child encounter.

III. DATA ACCESS

Privacy Constraints	BORN is a Prescribed Registry under Ontario's Personal Health Information Protection Act under its legacy name of the Ontario Perinatal Surveillance System. This status allows BORN to collect, use and disclose personal health information for purposes of facilitating or improving the provision of health care. All requests made to BORN Ontario for access to health data are managed in accordance with the provisions of the Ontario Personal Health Information Protection Act 2004 (PHIPA). Data requests are considered for purposes of research including quality assurance projects. Data may include personal health information and de-identified health information from databases for which BORN Ontario has custody. For more information, refer to "Review of the Children's Hospital of Eastern Ontario in respect of the Better Outcomes Registry and Network: A prescribed person under the Personal Health Information Protection Act 2004" (www.ipc.on.ca/images/Findings/2011-cheo-review.pdf)
	A Privacy Impact Assessment has been done for this database Yes
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	BORN maintains that stakeholder engagement is a fundamental principle of the "build project", the integration process which is currently underway. Database users have been asked to participate in the design, review and testing of the new system. Potential data users have been invited to participate in a survey (available here: http://www.bornontario.ca/data-dictionary/survey) in order to identify any errors or omissions in the new, proposed data dictionary. The new database interface will be developed using a phased approach to minimize the impact on users and maximize the opportunities to integrate feedback back into the system. Users will be provided information and training well in advance of anticipated changes. BORN consulted with an Aboriginal physician who is member of the perinatal research community for advice on developing a variable to replace the Aboriginal identifier in the old system. BORN plans to begin the first phase of consultation with Aboriginal groups early in 2012, directly related to use and disclosure of data related to congenital anomalies.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols No Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications:
	1. BORN produces a variety of scientific reports on a regular basis, delivered through a number of mechanisms; public health unit reports, Local Health Integration Network Regional Reports and research reports. These reports can be accessed from their website: www.bornontario.ca/reports 2. The aforementioned reports do not systematically report on ethno-cultural identifiers. Aboriginal identity was reported in the 2008 Ontario Perinatal Surveillance System Report available here: https://www.nidaydatabase.com/info/pdf/OPSS%202008_online.pdf

IV. DATA USE & REPORTING

Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: The information gathered will support the Ministry of Health and Long-Term Care, the Provincial Council for Maternal and Child Health, Local Health Integration Networks and Public Health Units of Ontario in measuring maternal-child health status and outcomes, developing responsive health policies and improving evaluation and accountability. Hospitals and midwifery groups, as well as Provincial Screening Programs, will leverage the information for planning, monitoring, performance management and quality improvement. Healthcare providers and women and families will be supported as BORN helps ensure individuals have been offered all of the resources available to them across the maternal/newborn care continuum. Finally, BORN will contribute to hypothesis-generating research and innovation.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use No Information will not be used or disseminated without consultation with stakeholders.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: The scientific manager at BORN says: it would be helpful if your group [i.e. the ethnocultural identifier working group at the Canadian Partnership Against Cancer] could work with us and others to help hospitals and health care providers understand that it is not discriminatory to ask about a person's aboriginal background. Health outcomes can only be improved when we are able to measure and report to groups on their outcomes. Health care providers also need help with learning the best way to ask this question. Limit the re-application of this ethno-cultural identification approach to other jurisdictions:
Additional Comments	In addition to routinely collecting information on maternal Aboriginal self-identification in the future, the current BORN system will collect information pertaining to the care provided to maternal/child pairs. Additional information added to the new database (while not a direct identifier) may be useful. For birth location, one of the new choices added is "Aboriginal birthing centre". As well, BORN will document the care provider attending the birth and one of the response options is "Aboriginal midwife".

4.4.3 Colorectal Cancer Screening Registry

I. DATABASE – Colorectal Cancer Screening Registry				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	Colorectal cancer is the second-leading cause of cancer death in Canada. Screening can detect colorectal cancer at its earliest stage when treatment is most effective, but in Ontario < 30% of the eligible population is being screened regularly. Cancer Care Ontario (CCO) and the Ontario Ministry of Health and Long Term Care (MOHLTC) launched Canada's first population-based, provincial colorectal cancer screening program - ColonCancerCheck (CCC) - in 2008. CCO developed InScreen to support the ColonCancerCheck screening program. InScreen is a Customer Relationship Management (CRM) software that works to identify Ontarians eligible for screening. It has the ability to send invitations for screening, notify when results are available, and facilitate screening recalls and reminders at appropriate intervals. InScreen also facilitates reports to primary care providers so they can proactively support their patients' screening needs.			
Custodian	Cancer Care Ontario			
	Mandate of Custodian: Improve the performance of the cancer system by driving quality, accountability and innovation in all cancer-related services.			
Purpose	Reduce deaths from colorectal cancer and support family physicians and nurse practitioners in providing the best possible colorectal cancer screening for their patients.			
	☒ Public Health & Surveillance ☒ screening ☐ immunization ☐ communicable disease ☐ other Specify	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy	☒ Service Delivery ☒ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data	☐ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☐ First Nation/North American Indian	☐ Inuit/Inuk	☐ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	CCC Registry does not include ethno-cultural identifiers, as none of its provincial source files include these (see Data Sources below). However, a number of First Nations, Inuit and Métis groups have expressed a need for better information on how cancer affects their communities, and how initiatives like screening can reduce the burden of cancer. In response to this, relevant regional cancer centres (RCCs) are currently working with their regional Aboriginal partners to 1) identify barriers to screening, 2) develop, in partnership, initiatives to reduce barriers to screening, and 3) implement initiatives that are culturally appropriate and sustainable. To do that, funding and supporting information (e.g. screening maps) are made available to qualified partnerships. To help establish accurate baseline information to evaluate the effect of new initiatives, these regional partnerships are working together to source local data.			

I. DATABASE – Colorectal Cancer Screening Registry	
	In the meantime, CCO - in collaboration with ICES (Institute for Clinical and Evaluative Studies) - has developed a Geospatial Analysis tool to apply statistical data to geographically based data to generate, for example, maps of screening rates. (See example at end of this profile) These maps can help local health care providers pinpoint areas of opportunity, and track progress over time. In the short term, this tool, which will have a web interface, can help local decision makers dimensionalize geographic variations where e.g. Dissemination Area (DA) codes fairly closely match First Nations reserves. Over time, as regional partnerships identify more appropriate sources of local data, these data can then be used within the InScreen database and its related software capabilities, such as the above Geospatial example, to develop culturally appropriate navigation approaches to improve screening for ethno-cultural groups while respecting principles of ownership, control, access and protection of the supporting information.
Data Sources	InScreen is a suite of information management/information technology solutions, originally created to support CCC, that acquires and integrates disparate data sets to create electronic screening records for Ontarians. This facilitates the persons cancer screening journey through invitations, recalls, reminders, result notification and reporting. Data feeds from the eight sources below are received into a data hub that loads, integrates and cleans the relevant data. Customer Relationship Management (CRM) software then creates and manages the electronic screening records and contact with screening participants and family physicians. Screening information is also stored in a data mart for subsequent use in reporting on screening services. 1. Ontario Cancer Registry (CCO) - collects colorectal cancer history; 2. Registered Persons Database (MOHLTC) - provides patient demographic information and death clearance; 3. Client Agency Program Enrolment (MOHLTC) - identifies patients enrolled with participating physicians practicing in Patient Enrolment Models; 4. Claims History Database (MOHLTC) - collects colonoscopy and FOBT procedure information; 5. Corporate Provider Database (MOHLTC) - health service provider registration and program affiliation information; 6. Health Network System (MOHLTC) - ColonCancerCheck FOBT kit distribution claims from participating pharmacists; 7. Laboratory Reporting Tool (Laboratories) - transmits ColonCancerCheck FOBT kit distribution, dispensing and results from 8 partner laboratories; 8. Colonoscopy Interim Reporting Tool - transmits colonoscopy procedure information from colonoscopy facilities.
	The Data Sources are currently being expanded to include additional data elements to support cervical and breast cancer screening in support of the Integrated Cancer Screening Program initiative.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): NA Month/year of latest available ethno-cultural identifiers: NA
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Specify
	Select One
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease

I. DATABASE – Colorectal Cancer Screening Registry

Users	Primary users of this database - Primary care physicians (data for their own patients only), ColonCancerCheck program staff; aggregate data are shared with broader audience which include the general public i.e. screening participants;
	Database also used by users external to Custodian
Populations	Population groups included in this database – Ontarians who meet the eligibility criteria for colon cancer screening;
Records	Total number of records in database: Currently, almost 4 million Ontarians are in CCC Registry, with this number increasing to almost 7 million in 2012 as part of the Integrated Cancer Screening (ICS) initiative.
Contact/ Questions	Support Organization Cancer Care Ontario Title of person in support role: Director, Prevention & Cancer Control Information Program Name: Richard Smith Phone: 416-217-1236 E-mail: richard.smith@cancercare.on.ca
Web site	www.cancercare.on.ca

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: While the database does not include ethno-cultural identifiers, it provides a mechanism for cancer screening partnerships with First Nations, Inuit and/or Métis health care and governance groups to explore data pooling options that respect Aboriginal principles of ownership, control, access and protection as well as provincial legislative and regulatory requirements for individual information privacy, security and confidentiality. Also, historically, many data linkage projects have been undertaken for the purpose of research. Linkage with InScreen could go beyond research, and directly affect 1) access to potentially life-saving screening services to under screened populations, as well as 2) the development of culturally more appropriate navigation to these services. Such improvements would fit with the mandate of a screening registry.
Data Quality	Comments on quality (optional)
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)

III. DATA ACCESS

Privacy Constraints	Cancer Care Ontario (CCO) is listed in the Regulation made under the Personal Health Information Protection Act, 2004 (PHIPA), s. 39(1)(c), as a “prescribed registry” in respect of its Colorectal Cancer Screening Registry. Prescribed registries are a specific class of organizations that are permitted under PHIPA to collect personal health information from health information custodians (without individuals’ consent) for the purposes of facilitating and improving health care. In turn, prescribed registries are permitted to use and disclose personal health information received from health information. custodians (without consent) for the same purposes. Prescribed registries are only permitted to collect, use, and disclose personal health information in this way once the organization : 1. puts privacy practices into place, 2. makes those practices publicly available, and 3. receives approval from the Information and Privacy Commissioner/Ontario (IPC)

III. DATA ACCESS

CCO and the Ministry of Health and Long-Term Care established ColonCancerCheck to manage the Colorectal Cancer Screening Registry, increase access to colorectal cancer screening, and ultimately reduce mortality due to colorectal cancer. ColonCancerCheck (i.e. CCO, as a prescribed person who compiles or maintains a registry of personal health information for purposes of facilitating or improving the provision of health care) met its prescribed registry requirements and received IPC approval of its privacy practices on April 7, 2008. As such, ColonCancerCheck may collect, use, and disclose colorectal cancer screening information about Ontarians in order to facilitate and improve the provision of health care, particularly colorectal cancer care.

ColonCancerCheck generally takes a consent-based approach to the disclosure of FOBT results to health care providers, despite the fact that it is authorized by law to make such disclosures without consent. For example, where an unattached participant receives a positive FOBT result and requires a referral for a colonoscopy, ColonCancerCheck obtains the unattached participant's oral consent before disclosing the participant's results and contact information to the provider providing follow-up care. Individuals may choose, at any time, not to be contacted by ColonCancerCheck. If the individual does not wish to be contacted by ColonCancerCheck, he or she must request to opt out of the ColonCancerCheck program.

ColonCancerCheck employs administrative, technical, and physical safeguards to protect the personal health information collected from laboratories and other sources.

- Administrative Safeguards: ColonCancerCheck describes its privacy practices in the ColonCancerCheck Privacy Policy, which staff must read, and privacy training sessions, which all staff must attend. Staff must also sign agreements verifying they understand and will adhere to ColonCancerCheck's privacy practices
- Technical Safeguards: Access to the Colorectal Cancer Screening Registry is controlled by usernames and passwords, protected by CCO's network security controls, and monitored by the CCO Systems Security Specialist
- Physical Safeguards: Access to the ColonCancerCheck office and the data centre, where the servers that support the Colorectal Cancer Screening Registry are housed, is controlled by access cards at doors and elevators, and monitored with video surveillance

Only ColonCancerCheck staff who require access to the Colorectal Cancer Screening Registry to perform their job functions have access to the personal health information. For example, ColonCancerCheck staff who are responsible for drafting invitation letters or notifying participants of their results, have access to the Registry. The ColonCancerCheck Data Steward is responsible for authorizing ColonCancerCheck staff's use of the Registry and confirming that such access is still appropriate. There is no external or internal access to the Registry by any users other than ColonCancerCheck staff.

Source: Ontario Ministry of Health and Long Term Care: http://www.mohltc.ca/en/pro/programs/coloncancercheck/privacy_faq.aspx, accessed Oct. 5, 2011

NOTE: In preparation for Integrated Cancer Screening, the Colorectal Cancer Screening Registry has received approval to be expanded to the Ontario Cancer Screening Registry (OCSR).

A Privacy Impact Assessment has been done for this database Yes

III. DATA ACCESS

First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Not Applicable An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions The CCC Registry database does not currently include Aboriginal-specific information; work to customize baseline assessments and program delivery to the needs of Aboriginal communities needs to engage the communities involved, and reflect their needs.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable | Inuit Land Claims research protocols Not Applicable | Métis requirements Not Applicable

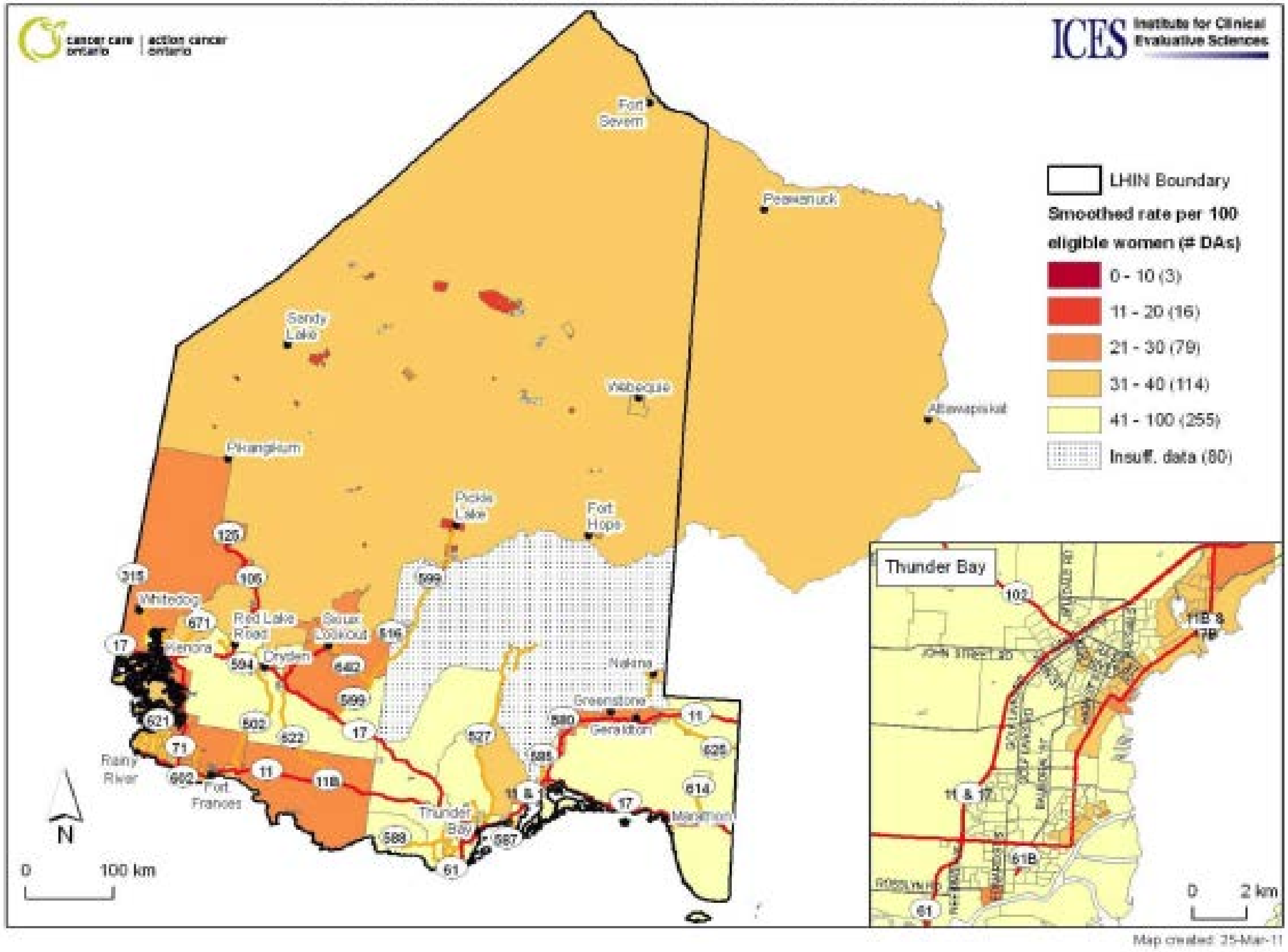
IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Screening Activity Reports: these reports are currently distributed to ~ 7,000 primary care physicians within Patient Enrolment Models (PEM), and include a) a patient list (all the physician's patients, and those patients who require follow-up), and b) a practice overview (tables/graphs showing patient screening status, screening activity comparisons, invitation follow-up status, etc.). 2. Screening Campaign Management: InScreen facilitates an eligible person's cancer screening journey through invitations, recalls, reminders, result notification and reporting.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. The Screening Activity Reports and Campaign Management activities are improving primary care capacity towards appropriate screening of patients, as well as improving patient capacity to appropriately choose to participate in screening programs; 2. Due to the success of the CCC Registry, InScreen and its impact on patient screening, awareness and prevention of colorectal cancer, the MOHLTC approved an Integrated Cancer Screening initiative, which will expand InScreen's data and technology to include breast and cervical cancer screening. The addition of breast and cervical cancer screening data will increase the number of screening records in what will then be known as the Ontario Cancer Screening Registry from four million to almost seven million by 2012.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Provincial and regional/ local cancer control & prevention partnerships have been, and continue to be engaged in discussions to enhance appropriate screening capacity.

IV. DATA USE & REPORTING

Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Below is an example of a 'screening map', which is an example of what could be produced with the technology and information delivered via InScreen:

**Endoscopies or Fecal Occult Blood Tests (FOBTs) among Women ages 50-74, 2009
North West LHIN by 2006 Dissemination Area (DA)**



4.4.4 Métis Nation Ontario Citizenship Registry

I. DATABASE – Métis Nation of Ontario Citizenship Registry	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The Métis Nation of Ontario (MNO) maintains the only recognized provincial Registry for Métis in Ontario. Métis people who are current residents of Ontario can make an application for citizenship to the MNO. The applications are assessed by an independent Registrar who approves for citizenship those applicants who meet the criteria set out in the National Definition for Métis, adopted at the Métis National Council's 18th General Assembly in 2002 and subsequently accepted by the MNO.
Custodian	Métis Nation of Ontario
	Mandate of Custodian: Some of the goals set out in the MNO Statement of Prime Purpose include: • Creating a Métis-specific governance structure for the implementation of the nation's inherent right to self-government in the province; • Establishing a credible and recognized identification system for Métis people within the province; • Focusing on 'nation building' through working together as a collective in order to support Métis citizens and communities; • Pursuing a rights-based agenda and proudly asserting the Métis existence as a distinct Aboriginal people within Ontario; • Protecting and preserving the distinct culture and heritage of the Métis Nation in the province; and, • Improving the social and economic well-being of Métis children, families and communities throughout the province.
Purpose	The Registry was established in 1994 to identify and register Métis citizens and harvesters who are eligible rights holders in the province of Ontario.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☒ On Métis register ☐ Other
	☐ Aboriginal ☐ Other
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: Continuous
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1994 Month/year of latest available ethno-cultural identifiers: Present
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other
	Postal Code

I. DATABASE – Métis Nation of Ontario Citizenship Registry

Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - The Métis Nation of Ontario Citizenship Registry is used primarily by the registrar to identify rights holders within the province. For example, Métis citizenship as defined by the registry is a criteria for eligibility to be listed on the Harvester Card Registry. Métis citizens holding harvester cards engaged in traditional Métis harvest activities will not be charged for these activities unless they are in violation of conservation or safety standards. Recently, the registry has also served as a basis for collaboration between the MNO and external researchers. The MNO has collaborated with provincial health agencies/research institutions such as the Institute for Clinical Evaluative Sciences (ICES) and Cancer Care Ontario (among others) to produce chronic disease reports based on linkages between administrative health databases and the registry. MNO Registry staff and external researchers have restricted access to the registry. For more information, see "Privacy" below.
	Database also used by users external to Custodian
Populations	Population groups included in this database – Métis residents of Ontario who self-identify as Métis and can provide genealogical evidence of Métis ancestry.
	Population Coverage - % of population targeted by the database that has been captured: As of 2006, the Ontario Métis registry had enrolled approximately 18% of the self-identifying Métis population in Ontario.
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: ~15,000 Annual number of records collected/updated:
Contact/ Questions	Support Organization Métis Nation of Ontario Title of person in support role: Manager of Health Care Initiatives Name: Lisa Pigeau Phone: (613) 798-1488 ext. 105 E-mail: lisap@Métisnation.org
Web site	http://www.Métisnation.org/registry.aspx

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s):

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Genealogical Information:

Please provide the first and last names as indicated below. **NOTE:** In the case of women, please use maiden names

Mother: ________________________ Does your Mother have Aboriginal ancestry? ☐ Yes ☐ No
Birth place: ________________________ If yes: ☐ Métis ☐ First Nations ☐ Inuit

Father: ________________________ Does your Father have Aboriginal ancestry? ☐ Yes ☐ No
Birth place: ________________________ If yes: ☐ Métis ☐ First Nations ☐ Inuit

Mother's Mother: ________________________ Does your Mother's Mother have Aboriginal ancestry? ☐ Yes ☐ No
Birth place: ________________________ If yes: ☐ Métis ☐ First Nations ☐ Inuit

Mother's Father: ________________________ Does you Mother's Father have Aboriginal ancestry? ☐ Yes ☐ No
Birth place: ________________________ If yes: ☐ Métis ☐ First Nations ☐ Inuit

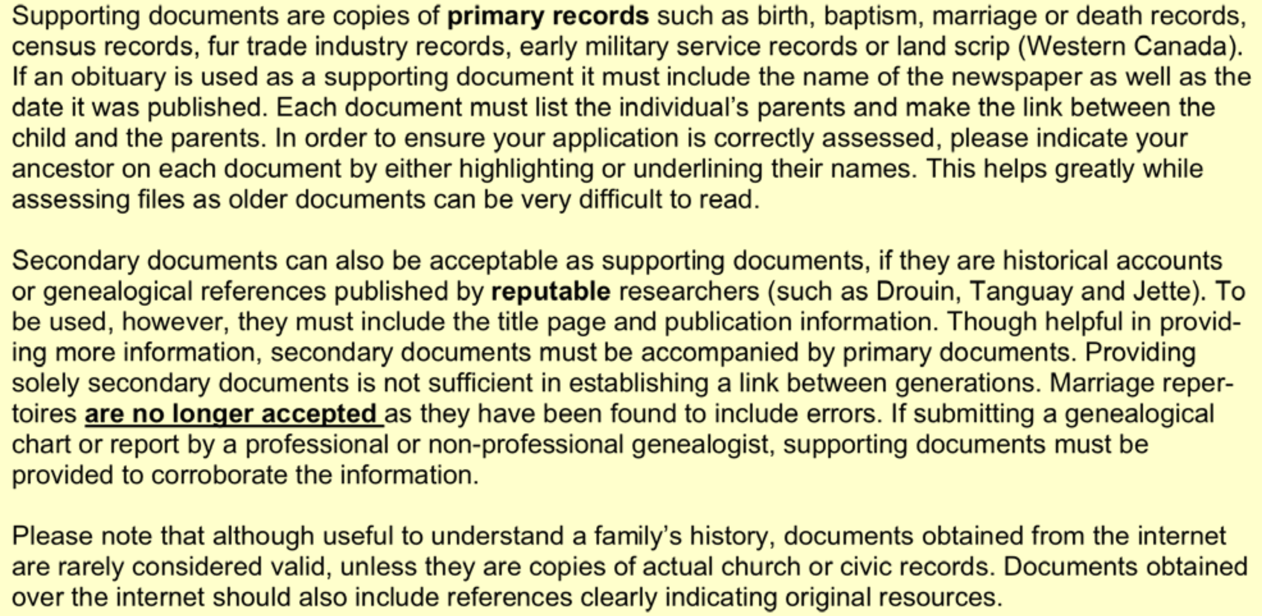
Father's Mother: ________________________ Does your Father's Mother have Aboriginal ancestry? ☐ Yes ☐ No
Birth place: ________________________ If yes: ☐ Métis ☐ First Nations ☐ Inuit

Father's Father: ________________________ Does your Father's Father have Aboriginal ancestry? ☐ Yes ☐ No
Birth place: ________________________ If yes: ☐ Métis ☐ First Nations ☐ Inuit

Please check (X) each box indicating that you are providing the following:

- ☐ MNO application form, fully completed (including the genealogical section)
- ☐ A genealogical chart, beginning with you and ending with your Métis ancestor (photocopy as many as needed)
- ☐ A photocopy of your long form birth **OR** baptismal certificate (the document must name your parent)
- ☐ A photocopy of a current photo identification document clearly establishing your residency in Ontario (e.g. student card, bus pass, drivers license)
- ☐ A clear photo with you name on the back - your copy of your photo ID is **NOT** sufficient for this purpose (maximum size 3" x 5")
- ☐ Documents confirming Métis ancestry
- ☐ Supporting documents linking every generation from you to your Métis ancestor (see below for more information
- ☐ A one time, non-refundable administration processing fee in the amount of $30.00 (Cheque or money order made payable to the Métis Nation of Ontario - **No cash please**)

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Supporting documents are copies of **primary records** such as birth, baptism, marriage or death records, census records, fur trade industry records, early military service records or land scrip (Western Canada). If an obituary is used as a supporting document it must include the name of the newspaper as well as the date it was published. Each document must list the individual's parents and make the link between the child and the parents. In order to ensure your application is correctly assessed, please indicate your ancestor on each document by either highlighting or underlining their names. This helps greatly while assessing files as older documents can be very difficult to read.

Secondary documents can also be acceptable as supporting documents, if they are historical accounts or genealogical references published by **reputable** researchers (such as Drouin, Tanguay and Jette). To be used, however, they must include the title page and publication information. Though helpful in providing more information, secondary documents must be accompanied by primary documents. Providing solely secondary documents is not sufficient in establishing a link between generations. Marriage repertoires **are no longer accepted** as they have been found to include errors. If submitting a genealogical chart or report by a professional or non-professional genealogist, supporting documents must be provided to corroborate the information.

Please note that although useful to understand a family's history, documents obtained from the internet are rarely considered valid, unless they are copies of actual church or civic records. Documents obtained over the internet should also include references clearly indicating original resources.

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen: This rigorous procedure was chosen in order to uphold the standards and definition laid out in the National Definition for Métis, adopted at the Métis National Council's 18th General Assembly in 2002 and subsequently accepted by the MNO. Three main components make up this definition:

1. Self-identification: This means that applicants to the MNO Registry must see themselves and identify themselves as distinctly Métis.
2. Historic Métis Nation Ancestry: This means that an applicant must have an ancestral connection to the historic Métis society (the "Historic Métis Nation"). This requires a genealogical connection to a "Métis ancestor" – not an Indian or aboriginal ancestor.
3. Community Acceptance: This means being accepted as Métis by the right-bearing Métis collective – the Métis Nation. Registration as a citizen of MNO constitutes acceptance by the rights-bearing Métis community.

More information about the design and rationale of the registry can be found in the following document:
Métis Nation of Ontario. Interim Registry Policy Materials. http://www.Métisnation.org/media/83726/mno_interim_registry_package.pdf#Policy

Ethno-cultural identity question(s) has been tested No
Test report re question design is available No
Name/citation for test report: N/A

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The Métis have typically been under-represented in health research compared to other Aboriginal groups. This is likely in part due to difficulties associated with identifying Métis people within administrative data sources and the fact that the Métis do not typically live within specific geographic boundaries. The Métis Nation of Ontario Citizenship Registry can act as a cohort for linkage studies.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated	No
	Test /pilot/ evaluation report is available	No
	Title/ citation for report: See above.	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used:	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	Comparison of the registry to the self-identifying Métis population in Ontario as defined by the 2006 Census of the Population (long form) shows a modest but significant skew in the registry toward inclusion of men, residents of rural areas and older individuals. See table below. Whilst not proven, this may relate to the fact that registered Métis citizenship is required to be eligible for a Harvester Card, which grants the cardholder rights to participate in traditional Métis harvest activities without paying the fees that may otherwise be associated with these activities. In the table below, there is an asterisk (*) next to the youngest age category, to highlight that for the Métis citizens, only individuals aged 18-24 were included. However, for the census, data is only publicly available for the 15-24 age range.	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Métis Nation of Ontario Citizens Registry Linkage		Ontario Métis people identified in the 2006 census	
	n	**%**	**n**	**%**
TOTAL	13,439	100.00	73,605	100.00
Sex				
Female	6,169	45.90	37,025	50.30
Male	7,270	54.10	36,580	49.70
Age				
(15 or 18)-24*	1,541	11.47	13,260	22.79
25-34	2,676	19.91	10,510	18.06
35-44	2,780	20.69	12,075	20.75
45-54	3,114	23.17	11,660	20.04
55-64	1,825	13.58	6,875	11.82
65 and over	1,503	11.19	3,800	6.53
Rurality				
Urban	8,816	68.97	52,895	71.86
Rural	4,170	31.03	20,475	27.82
On-reserve			235	0.32

Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: Each application for citizenship must go through a rigorous approval process at the MNO. The review of individual ancestry records consumes a significant amount of time and human resources.

III. DATA ACCESS

Privacy Constraints

All personal information in the Registry shall be kept strictly confidential and no personal information from a file may be disclosed to anyone, including members of the Provisional Council of the MNO, without the consent of the applicant or citizen. Aggregate data from the Registry may be collected and used for research or other purposes provided it does not disclose personal information without the consent of the applicant or citizen.

A Privacy Impact Assessment has been done for this database Select One

Information has been used for secondary purposes Yes

If yes, examples of secondary data use: The Métis Nation of Ontario Healing and Wellness Branch's Chronic Disease Surveillance Project (CDSP) is a ground-breaking health surveillance initiative focused on gathering Métis specific data on health and health care. Part of this project includes population-based studies to determine the rate of chronic disease in Métis people in Ontario as well as outcomes from healthcare. These studies are achieved in partnership with the Institute for Clinical Evaluative Sciences (ICES), a government supported scientific research institute dedicated to understanding illness rates and treatment outcomes. The findings will be useful in determining the health priorities of Métis people in Ontario as well as developing and delivering health programs tailored to their specific needs.

First Nations, Inuit, and/or Métis Engagement

First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes

An MOU or formal agreement governing development and/or use of the database is in place Not Applicable

First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as

☒ Designer (e.g. of question) | ☒ Collector of data | ☒ Custodian | ☐ Analyst | ☒ User for decisions

The MNO registry is controlled, maintained and designed by the MNO and its staff.

OCAP

The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:

First Nations OCAP principles Not Applicable | Inuit Land Claims research protocols Not Applicable | Métis requirements Yes

IV. DATA USE & REPORTING

Data Products

Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes

Examples of analyses, reports, publications:

In 2010, the MNO, with funding from the Public Health Agency of Canada, commissioned a series of chronic disease "Technical Reports". These reports were produced through collaboration between the MNO and ICES. The MNO co-ordinated the projects, provided a list or registrants and a contributed their cultural perspective. ICES provided the data and methodological expertise.

1. Shah B, Cauch-Dudek K, Pigeau L. Diabetes Prevalence and Care in the Métis Population of Ontario, Canada. Diabetes care. 2011.
2. Klein-Geltink J, Cascagnette P, Gershon A, To T, Crighton EJ, Gravelle M, Pigeau L, MacQuarrie, J. Chronic Respiratory Disease in the Métis Nation of Ontario (Technical Report). Prepared for the Métis Nation of Ontario (MNO). (Forthcoming)
3. Atzema C, Kapral M, Klein-Geltink J, Asllani E, Gravelle M, Pigeau L, MacQuarrie J, Lyons D. Cardiovascular Disease in the Métis Nation of Ontario. April 2010. http://www.Métisnation.org/media/135527/mno%20cv%20disease%20lay%20report,%20final.pdf
4. Klein-Geltink J, Saskin R, Manno M, Urbach D, Henry D, Gravelle M, Pigeau L, MacQuarrie J, Lyons D. Cancer in the Métis Nation of Ontario (Technical Report). November 2010. http://www.Métisnation.org/media/135515/mno%20cancer%20lay%20report,%20final.pdf

IV. DATA USE & REPORTING	
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions:
	1. Findings from the technical report "Cancer in the Métis Nation of Ontario" will be integrated into the Aboriginal Cancer Strategy II report, currently being produced by Cancer Care Ontario. 2. Each of the technical reports produced (see "Data Products" above) will be followed by a Clinical Significance Report. The Clinical Significance Reports will be produced by the MNO in collaboration with a subject area expert. The findings of the Technical and Clinical Significance Reports will be used by the Healing and Wellness Branch of the MNO to inform future chronic disease prevention planning and programming.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes
	The technical reports have been re-written in lay language and posted on the MNO website. See: http://www.Métisnation.org/programs/health--wellness/chronic-disease-studies.aspx
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification No
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Rigorous application procedure ensures that every member meets the National Definition of Métis. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Very time consuming to verify all the genealogical information. At any given time, there are thousands of pending applications.

4.4.5 Ontario Cancer Registry / Indian Register Linkage (1968-2001)

I. DATABASE – Ontario Cancer Registry/Indian Register Linkage (1968 - 2001)	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	A cohort of 141,920 Ontario Registered First Nations was created from registration files maintained by Aboriginal Affairs and Northern Development Canada. Cancers and deaths were ascertained by linkage to the provincial cancer registry and mortality file, which also provided general population comparison data.
Custodian	Cancer Care Ontario
	Mandate of Custodian: To improve the performance of the cancer system by driving quality, accountability and innovation in all cancer-related services.
Purpose	To determine cancer incidence, mortality and survival in Ontario First Nations people diagnosed with, or dying from, cancer between 1968 and 2001 and to compare these with rates in the Ontario population.
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☒ other Cancer
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☐ program/service ☐ public policy
	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other
	☐ Aboriginal ☐ Other
Data Sources	1. The Indian Register, limited to members of Ontario bands 2. Ontario Mortality Database, 1968-2005 3. Ontario Cancer Registry, 1968-2001
	Cancer incidence was truncated at 2001 due to concerns about incomplete linkage to the Indian Register. Mortality was followed up until 2005 for survival analysis of cancer cases.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1968 Month/year of latest available ethno-cultural identifiers: 1991
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other

I. DATABASE – Ontario Cancer Registry/Indian Register Linkage (1968 - 2001)

	Select One
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Cancer Care Ontario
	Only users internal to Custodian use the database
Populations	Population groups included in this database – First Nations registered with Ontario bands
Records	Total number of records in database: 141,290 people
Contact/Questions	Support Organization Cancer Care Ontario Title of person in support role: Senior Scientist and Director, Surveillance, Prevention & Cancer Control Name: Loraine D. Marrett Phone: 416-217-1381 E-mail: loraine.marrett@cancercare.on.ca
Web site	www.cancercare.on.ca

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: This linkage yielded the first large study of cancer incidence, mortality and survival in First Nations in Canada and overcame many limitations of earlier, smaller studies. Advantages of this study over others include: a relatively large number of cancer in First Nations; a long follow-up time; a large and representative population of First Nations (both on and off reserve) from which both those with cancer were identified and person-years at risk were calculated. Because of these strengths, the authors were able to estimate stable estimates of cancer incidence, mortality and survival rates by site and time for Ontario First Nations and the Ontario general population.
Data Quality	There is some concern that deaths and cancers were incompletely ascertained, especially after 1991. This would lead to an overestimate of the number of people who were alive and at risk of cancer in the cohort and an underestimate of the number with cancer and therefore underestimated cancer incidence rates.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes

III. DATA ACCESS

Privacy Constraints	The linkage was approved under a Data Sharing Agreement with Aboriginal Affairs and Northern Development Canada (AANDC). The request to AANDC (previously INAC) was made in 1991, prior to the introduction of Privacy Impact Assessments.
	A Privacy Impact Assessment has been done for this database No
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as
	☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☒ User for decisions
	The linkage was done prior to the introduction of OCAP.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:
	First Nations OCAP principles No | Inuit Land Claims research protocols Not Applicable | Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications:
	1. Marrett LD, Chaudhry M. Cancer incidence and mortality in Ontario First Nations, 1968-1991 (Canada). Cancer Causes & Control. 2003 Apr;14(3):259-68. 2. Numerous presentations and reports to First Nations, as well as to non-First Nations researchers, policy-makers and health system administrators.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions:
	Findings arising from this linkage have informed the Aboriginal Cancer Strategy at Cancer Care Ontario, among others. This model of linking the Indian Register to provincial cancer registries has since been used and informed policy in a number of other jurisdictions.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes
	See "Data Products" and "Evidence-Informed Decisions" above.
Application of First Nations, Inuit and/or Métis Identification	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Since this linkage was conducted, similar methodology has been used in other jurisdictions, including Manitoba. (For more information see profile for Manitoba Registered First Nations Population Database) There are plans to repeat this linkage in Ontario via a partnership between Chiefs of Ontario, the Institute for Clinical and Evaluative Sciences, Cancer Care Ontario and First Nations Inuit Health (Ontario).

IV. DATA USE & REPORTING	
Approach to Other Jurisdictions	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Limit the re-application of this ethno-cultural identification approach to other jurisdictions:
Additional Comments	

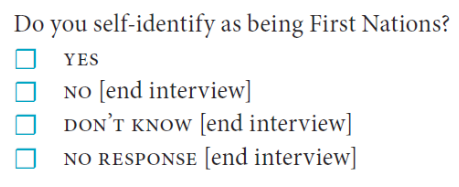
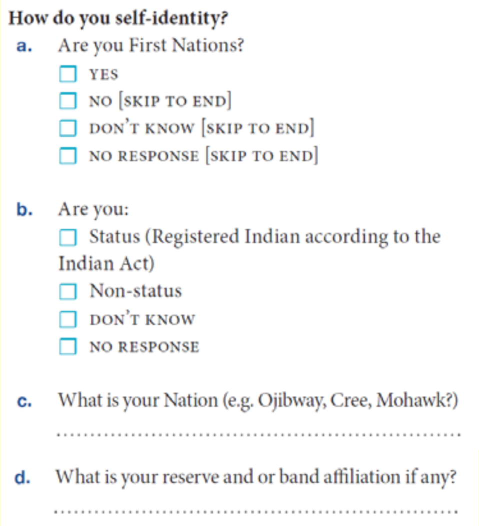
4.4.6 Our Health Counts – Baseline Population Health Database for Urban Aboriginal People in Ontario

I.	**DATABASE – Our Health Counts - Baseline Population Health Database for Urban Aboriginal People in Ontario**			
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	Through partnerships with key Aboriginal stakeholders, a "respectful health assessment survey" was developed and administered to urban Aboriginal people identified through respondent-driven sampling. The survey collected information on a wide range of health topics. Following participation in the survey, respondents were asked whether they would provide their Ontario Health Insurance Plan (OHIP) number in order to link their survey responses to health care system usage information available through the Institute for Clinical Evaluative Sciences (ICES). The opportunity to connect with ICES enabled the Our Health Counts research team to produce, for the first time, urban Aboriginal population-based rates of emergency room use, hospital admission and participation in preventative screening programs, including breast, cervical and colorectal cancer screening. There were three project community sites: First Nations in Hamilton, Inuit in Ottawa, and Métis in Ottawa. The First Nations report has been released and is primarily described here. The Inuit and Métis reports have yet to be released.			
Custodian	The governing council for Our Health Counts is composed of representatives from the Ontario Federation of Indian Friendship Centres, the Métis Nation of Ontario, the Tungasuvvingat Inuit Family Health Team and the Ontario Native Women's Association. The Centre for Inner City Health at St. Michael's Hospital and the Institute for Clinical Evaluative Sciences are research partners on the project. The Respectful Health Assessment Survey Data Set for Urban First Nation people living in Hamilton, Ontario is directed, operated, controlled and owned by De dwa da nye>s Aboriginal Health Access Centre and the Ontario Federation of Indian Friendship Centres on behalf of the First Nations people living in Hamilton.			
	Mandate of Custodian: The mission of the De dwa da nye>s Aboriginal Health Access Centre is to improve the wellness of Aboriginal individuals and of the Aboriginal community by providing services which respect people as individuals with a distinctive cultural identity and distinctive values and beliefs.			
Purpose	The goal of the Our Health Counts (OHC) project was to work in partnership with Aboriginal organizational stakeholders to develop a baseline population health database for urban Aboriginal people living in Ontario that is immediately accessible, useful, and culturally relevant to local, small region, and provincial policy makers.			
	☒ Public Health & Surveillance ☒ screening ☒ immunization ☒ communicable disease ☐ other Specify	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☐ program/service ☒ public policy	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☐ Aboriginal
	☒ Status (registered, treaty) ☒ Non-status ☐ On-reserve ☒ Off-reserve ☒ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	As mentioned in "Description" above, Inuit and Métis residing in Ottawa will be included through the publication of community-specific research at a later date.			
Status & Update	Database status Inactive	Database update frequency 1-off Frequency of Updates:		

I. DATABASE – Our Health Counts - Baseline Population Health Database for Urban Aboriginal People in Ontario

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 2009 Month/year of latest available ethno-cultural identifiers: 2010
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Neighbourhood
	Postal Code
Service Domain	☒ Acute Care ☒ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☒ Primary Care ☒ Drugs ☒ Cancer ☒ Diabetes ☒ Renal Dialysis ☒ Immunization ☒ Communicable Disease
Users	Primary users of this database - The "Respectful Health Assessment Survey" will be used by research partners from the participating organizations including the Ontario Federation of Indian Friendship Centres, the Métis Nation of Ontario, the Tungasuvvingat Inuit Family Health Team, the Ontario Native Women's Association and St. Michael's Hospital. The database produced as a result of linkage with health utilization databases at ICES was done internally at ICES by ICES staff, and a data sharing agreement was negotiated that respected First Nations, Inuit and Métis desires to self-govern their health information. For more information, see Appendices of the "Our Health Counts" report available here: http://aboriginalhealthcentre.com/wordpress/wp-content/uploads/2011/12/Our-Health-Counts-Community-Report-First-Nations-and-Children-Hamilton-ON.pdf
	Only users internal to Custodian use the database
Populations	Population groups included in this database – Urban First Nations, Inuit and Métis. A respondent driven sampling (RDS) technique was used to recruit individuals to be interviewed for the study. RDS has been used in other settings to capture members of communities that might be otherwise hard to reach (i.e. the homeless). In this study, tickets were given to each participant who completed an interview, and the participants could give these tickets to other First Nations, Inuit or Métis people they knew, including friends and family. Recruiters were provided with $10 for every person that they referred to the study. The findings were adjusted for bias using RDS statistics to take into account the fact that participants were connected through social networks. To be eligible for the First Nations arm of the study, individuals had to be living in the City of Hamilton at the time of survey administration.
	Population Coverage - % of population targeted by the database that has been captured: NA
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: 790 First Nations respondents from City of Hamilton Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Title of person in support role: Name: Phone: E-mail:
Web site	http://aboriginalhealthcentre.com/services/our-health-counts/

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Different questions were used for each of the community sites. For the Hamilton study, to determine eligibility for the study:  Do you self-identify as being First Nations? ☐ YES ☐ NO [end interview] ☐ DON'T KNOW [end interview] ☐ NO RESPONSE [end interview] In the core survey:  **How do you self-identity?** **a.** Are you First Nations? ☐ YES ☐ NO [SKIP TO END] ☐ DON'T KNOW [SKIP TO END] ☐ NO RESPONSE [SKIP TO END] **b.** Are you: ☐ Status (Registered Indian according to the Indian Act) ☐ Non-status ☐ DON'T KNOW ☐ NO RESPONSE **c.** What is your Nation (e.g. Ojibway, Cree, Mohawk?) .... **d.** What is your reserve and or band affiliation if any? .... Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached
Question Design	Reason why the above question and/or identifier was chosen: Survey tools were piloted with First Nations community members who were otherwise ineligible for the survey (i.e. their residence was outside eligible jurisdictions). Two rounds of piloting (which included informed verbal consent) occurred. Each session provided valuable suggestions on how to improve the survey, how to adjust language to become more respectful, and how to promote a logical flow to the questions.
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available No Name/citation for test report:
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Over 60% of Ontario's Aboriginal population lives in urban areas. Public health assessment data for this population is almost non-existent, despite its size (150,570 persons). This is primarily due to the inability of Ontario's current

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	health information system to identify urban Aboriginal individuals in its health datasets. Health assessment data that do exist are most often program or non-random survey based, not population based. Program-based sampling typically restricts coverage to those who are accessing services and therefore under-represents the under-served members of the community. When urban Aboriginal people have been included in census-based national surveys, these surveys are underpowered and urban First Nations, Inuit, and Métis data cannot be disaggregated. From a population and public health perspective, this near absence of population based health assessment data is extremely concerning, particularly given the known disparities in social determinants of health. This project identified the health indicators that are relevant to Canada's Aboriginal Peoples and generated much needed health data-sets specific to this under-served population.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated	Select One
	Test /pilot/ evaluation report is available	Select One
	Title/ citation for report:	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality (optional)	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No This project was funded by the Ontario Federation of Indian Friendship Centres, the Ministry of Health and Long-Term Care Aboriginal Health Transition Fund, and the Centre for Research on Inner City Health (CRICH) at Saint Michael’s Hospital. The Institute for Clinical Evaluative Sciences (ICES) contributed the costs of the in-house ICES data analysis and Dr. Smylie was supported by a Canadian Institutes for Health Research New Investigator in Knowledge Translation award during the course of the project.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers	Select One
	Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	The project was subject to a Community-St. Michael's Hospital Research Agreement, which had as one of its principles respect of the individual and collective privacy rights of the Ontario Federation of Indian Friendship Centres (OFIFC) and De dwa da dehs neh>s Aboriginal Health Access Centre (AHAC) staff. In this agreement, OFIFC and AHAC and the CRICH at St. Michael’s Hospital (SMH) confirmed their respect for the privacy of individual participants in the research project. OFIFC and AHAC, and CRICH/SMH agreed to follow applicable privacy laws and regulations and to notify each other if

III. DATA ACCESS

	either received a complaint about breach of privacy. ICES has in place the practices and procedures necessary under subsection (3). 2004, c. 3, Sched. A, s.45 (1) to protect the privacy of individuals and the confidentiality and security of personal health information it receives.
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Yes First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☒ Collector of data ☒ Custodian ☒ Analyst ☒ User for decisions
	Urban Inuit, First Nations and Métis organizations and community members successfully partnered with provincial Aboriginal organizations and academic researchers in the collection, governance, management, analysis and documentation of their own urban health databases. The project was carried out using community-based participatory research methods. The approach promoted balance in the relationships between the Aboriginal organizational partners, academic research team members, Aboriginal community participants and collaborating Aboriginal and non-Aboriginal organizations throughout the health information adaptation process, from initiation to dissemination. A Memorandum of Understanding is published as an appendix to the cited Hamilton report.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Yes | Inuit Land Claims research protocols Select One | Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications:
	The Our Health Counts project is committed to knowledge dissemination, application and contribution to future projects. More specifically, the stated objectives of the project include the intent to: • Support community-based, small region, and provincial uptake and application of health data generated to health policies, programs, and services for First Nations, Inuit, and Métis. • Build on the outcomes of this study to design future longitudinal health studies in partnership with First Nations, Inuit, and Métis governing/organizational stakeholders as well as additional strategies to improve the quality of First Nations, Inuit, and Métis health data in Ontario. • Share study results with First Nations, Inuit, and Métis stakeholders in other provinces and territories to contribute to the development of urban Aboriginal health data enhancement strategies. This process has begun with the publication of the First Nations report from Hamilton: 1. Smylie J, Firestone M, Cochran L, Prince C, Maracle S, Morley M, Mayo S, Spiller T, McPherson B. Our Health Counts: Urban Aboriginal Health Database Research Project Community Report. First Nations Adults and Children. Hamilton, ON. December 2011. Full report available at: http://aboriginalhealthcentre.com/wordpress/wp-content/uploads/2011/12/Our-Health-Counts-Community-Report-First-Nations-and-Children-Hamilton-ON.pdf
Evidence-	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One

IV. DATA USE & REPORTING

informed Decisions	Examples of evidence-informed decisions: The report makes policy recommendations to federal, provincial and municipal government as well as local and provincial agencies in order to improve the health and well-being of urban aboriginals.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Limit the re-application of this ethno-cultural identification approach to other jurisdictions:
Additional Comments	

4.4.7 Tri-Hospital Health Equity Data Collection Project

I. DATABASE – Tri-Hospital Health Equity Data Collection Project	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NV ☒ Other Toronto
Description	Three Toronto hospitals (Mount Sinai Hospital, St. Michael's Hospital, and Centre for Addiction and Mental Health) as well as Toronto Public Health are piloting a socio-demographic data collection tool and link the results to health outcomes. The preparation for this pilot took place during 2010 and 2011, and included a literature review, consultations with stakeholders and experts, and the development of a data collection tool. The pilot will start by January 2012 and is expected to run for 6 months.
Custodian	Each of the four participating organizations will hold their own patient database. For purposes of the pilot, the demographic data will be completely hidden. If the pilot leads to a broad-based patient roll-out, patients will be asked for permission to retain the data, and link it to their health record for confidential viewing by health care clinicians.
	Mandate of Custodian: Toronto Public Health (TPH) works in many ways to improve the overall health of the population and to overcome health inequalities. Mount Sinai Hospital is dedicated to discovering and delivering the best patient care with the heart and values true to our heritage. St. Michael's has a longstanding commitment to affirm and protect the right to accessible, inclusive, secure, and respectful health care for all patients. CAMH combines clinical care, research, education, policy development and health promotion to help transform the lives of people affected by mental health and addiction issues. All four pilot participants share a commitment to excellence in patient/ client care, health equity, learning and improvement.
Purpose	Work towards a model for hospitals to gather patient socio-demographic data that can be linked to patient-level health outcomes data to reduce health disparities where these exist. Key learning objectives at the pilot stage: 1) which socio-demographic data to collect; 2) what questions to ask and how to ask them; 3) the most effective ways to gather sensitive personal information; 4) IT solutions that will integrate the collection of socio-demographic patient data into hospital systems.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other Specify
	☒ Aboriginal ☒ Other Aboriginal non-Canadian
	The data collection tool, which has been developed collaboratively with the four pilot sites and numerous experts and stakeholders has evolved considerably in the course of about 50 iterations/ versions over two years. It currently contains 15 questions on demographic topics that research has shown may be associated with lack of equity in access to service, care delivery and/or outcomes. Topics include: race, language, disability, sexual orientation, gender, place of birth, income and age. Aboriginal identification/affiliation may occur under four of these topics: 1) Race (includes the option to describe one's race as First Nation, Inuit, Non-Status Indian, Métis, Aboriginal person from outside Canada … alongside with other choices, such as Asian, Black, Middle Eastern, etc.); 2) Language (includes Ojibway and Oji-Cree); 3) Sexual orientation (includes "two-spirit"); 4) Religion (includes "native spirituality").

I. DATABASE – Tri-Hospital Health Equity Data Collection Project

Status & Update	Database status Inactive Database update frequency Select One Frequency of Updates: no data collected yet.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): pilot:1/2012 Month/year of latest available ethno-cultural identifiers:
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify Select One
Service Domain	☒ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☒ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☒ Communicable Disease
Users	Primary users of this database - Clinicians, hospital/ program administrators, diversity & community integration specialists, quality improvement & performance measurement decision support. While users outside of the hospitals/ Toronto Public Health may use outputs (aggregate data, reports) from the envisioned data holdings, identifiable patient records would stay with the individual custodians, and be subject to the same rigorous confidentiality protection as other patient information. Database also used by users external to Custodian
Populations	Population groups included in this database – In-patient and out-patient populations of the 3 hospitals and Toronto Public Health. During the pilot phase, only selected populations and their care providers will be involved from e.g. primary care, out-patient preventative care for chronic diseases including asthma, outpatient schizophrenia and sexual health clinics. Population Coverage - % of population targeted by the database that has been captured: Eventually, 100% of the hospital/ public health's patient/ client populations would be covered. During the pilot, only a small subset, e.g. 400 patients / site. Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: N/A Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Mt. Sinai Hospital Title of person in support role: Director Diversity and Human Rights Name: Marylin Kanee Phone: (416) 586-4800 ext. 4722 E-mail: mkanee@mtsinai.on.ca
Web site	http://www.mountsinai.on.ca/about_us/who-we-are/diversity-human-rights/

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): A full description of the data collection tool, together with pilot learning of its use, is expected to be published by the end of 2012. Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design	Reason why the above question and/or identifier was chosen: A 2-year iterative process with numerous experts and stakeholders has attempted to pinpoint the topic areas - and associated questions - that are most likely to be associated with discrimination and inequities in care and health outcomes. The purpose of the pilot is to validate - among others - whether these are the right topics and questions.	
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report: An evaluation will be done upon completion of the pilot.	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Pending a full evaluation of the pilot test, there may be important learning about ethno-cultural identification along a number of parameters (see Purpose above); this includes identification of topics that could be important to health and healing of First Nations, Inuit and/or Métis people in the areas of language (e.g. the ability to provide translation from and to Ojibway or Oji-Cree), spirituality (e.g. Mount Sinai has experience working with their Fire Marshall - to facilitate a smudging ceremony), and communication that supports patients to express themselves and their needs in culturally sensitive ways. The pilot is also expected to provide learning on the method of asking the questions, which includes the ability for the patient to provide the information via an electronic interface (tablet) - which might save staff time, and administration by clinicians, clerical staff or at the bedside with a research assistant.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No Test /pilot/ evaluation report is available No Title/ citation for report: Expected in 2012.	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report:	
	The pilot project includes training materials and communication tools for care providers and patients. A full description of the data collection tool, together with pilot learning of its use, is expected to be published by end 2012.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Select One Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database: A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Not Applicable If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	All four partners regularly engage with Aboriginal groups on ways to improve equitable service, including the Equity Data Collection Project. For example, Noojimawin Health Authority - an urban and rural Aboriginal Health Planning Authority that focuses on research, data collection, and analysis, communication, information sharing, and planning related to community health programs and services - is a key partner in developing new initiatives and pilot partners participate in Noojimwin Health Authority's Aboriginal Health Equity Advisory Committee. Another example is Mount Sinai Hospital's consultations with ten distinct cultural communities, including Aboriginal people, that have traditionally experienced barriers to health care, to ask their views on how to improve access to health care and close existing health disparities. Cf. "Made in Sinai Health Equity Competencies: Delivering Healthcare to Diverse Communities. Community Consultation Summary Findings. Ruby Lam, A project of the Mount Sinai Hospital Diversity and Human Rights Committee. A third illustration is the staffing and approach Mount Sinai Hospital is taking to engaging community groups in matters affecting care; this includes a Community Engagement Framework and 2010-2013 Community Partnership Strategy that are facilitated by the hospital's Director of Community Integration.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No | Inuit Land Claims research protocols No | Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications:
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions:
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes See comments above under "first Nations, Inuit and/or Métis Engagement".
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One A key objective of the project is to ensure knowledge exchange of successful methodologies with other institutions.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Challenges that have been recognized from the start include 1) lack of IT interoperability of patient records, resulting in potential duplication of effort in terms of collecting and recording socio-demographic data; 2) negative association/ misunderstanding among patients and service providers about the need to collect demographic data; 3) the body of research on socio-demographic data collection is limited.
Additional Comments	The Tri-Hospital Health Equity Data Collection Project cannot been seen in isolation from the strategic work in a number of Toronto and Ontario organizations over many years. These include (i) the vision, mission and values of Toronto's 18 hospitals and public health, which all have an important focus on client service, quality and equity; one of the expressions of that focus is the Hospital Collaborative on Marginalized Populations, which works together to develop, analyze and evaluate formal health equity plans at hospitals. (ii) the participation of research institutes with a long history of evidence-informed health equity research and capacity to support the development and evaluation of new equity initiatives (e.g. Wellesley Institute and Centre for Research on Inner City Health (CRICH); (iii) the Toronto Central LHIN Strategic Plan, which focuses on re-orienting the health care system around people and communities through quality, equity and sustainability; (iv) the adoption in 2010 of the Excellent Care for All Act which puts patients first by improving the quality and value of the patient experience through the application of evidence-based health care. It aims to improve health care for all Ontarians while ensuring that the system is there for future generations. Together, these organizations are starting to build the will, evidence and experience toward more equitable health care that can reduce disparities. Based on interviews with 12 key informants who have collected socio-demographic client data in Toronto and the US a number of important parameters to successful socio-demographic data collection were identified: 1. You need to communicate transparency and clarity of purpose, i.e. equity and quality of care; 2. Don't ask questions about income - or leave it until last; people will stop filling out the form once they come to the income question; 3. Sequence questions - from least to most sensitive: first ask the things that you're born with, then things that are choices, and lastly things that are choices that other people might not like; 4. Ethnicity is more important than race for telling us about culture and language …. but it is a large and not always well-defined topic; 5. Race and ethnicity should be self-identified; 6. When you ask socio-demographic questions, and who asks will affect the response; 7. Frontline staff need to understand and buy in to the purpose of data collection; otherwise they may be uncomfortable, non-compliant or game the system.

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.5 QUEBEC

4.5.1 Nunavik Inuit Beneficiaries List

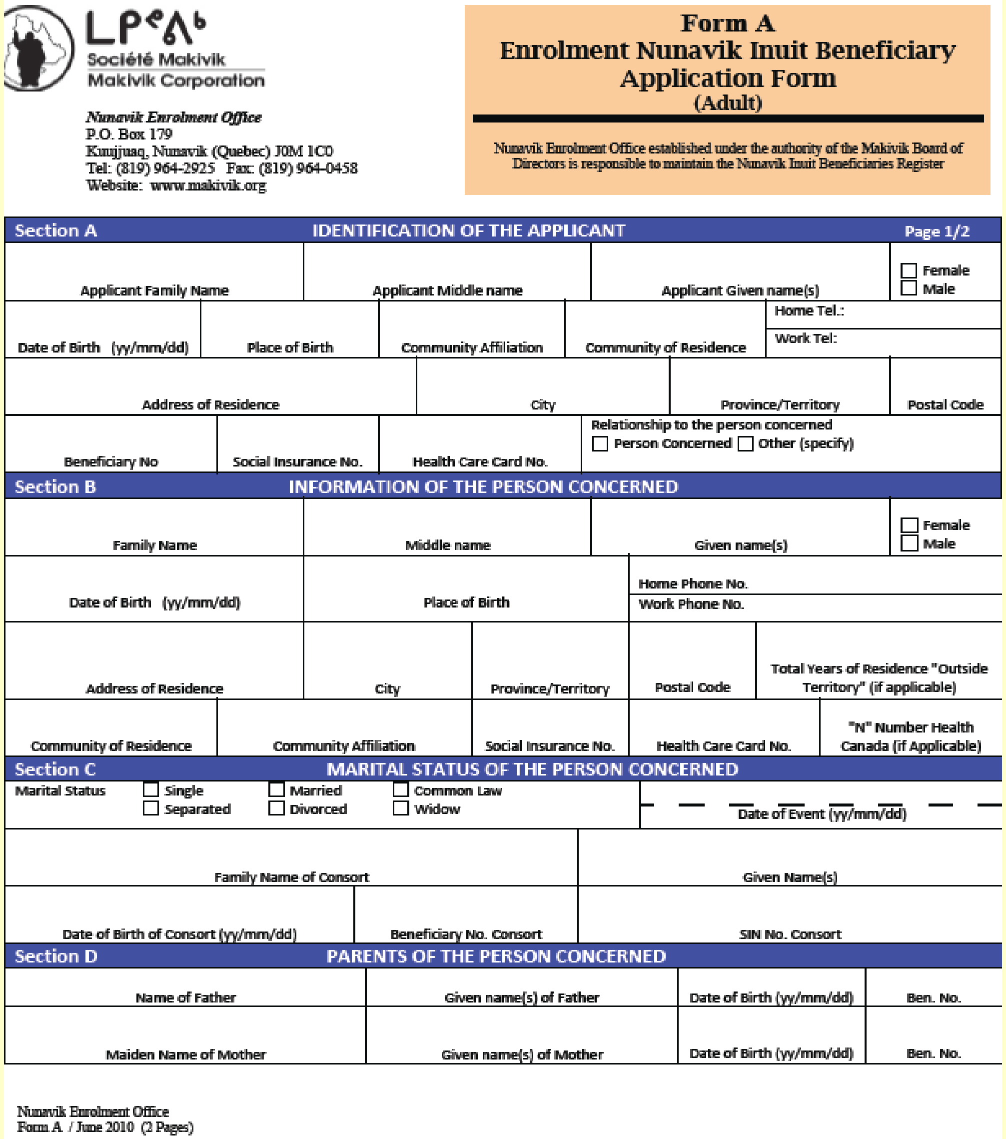
I. DATABASE – Nunavik Inuit Beneficiaries Register	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☒ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YK ☐ NT ☐ NV ☒ Other Nunavik
Description	The James Bay And Northern Quebec Agreement was a land claim settlement, approved in 1975 by the Cree and Inuit of northern Quebec, and later slightly modified in 1978 by the North-eastern Quebec Agreement, through which Quebec's Naskapi First Nations joined the treaty. The agreement covered economic development and property issues in northern Quebec, as well as establishing a number of cultural, social and governmental institutions for First Nations and Inuit who are members of the communities involved in the treaties. Responsibility for health and social services in Cree communities is the responsibility of the Cree Board of Health and Social Services of James Bay. In Nunavik, these services are provided by the Nunavik Regional Board of Health and Social Services (NRBHSS). The Nunavik Inuit Beneficiaries Register is composed of the two (2) following lists, maintained and updated in accordance with the decisions of the Community Enrolment Committees and of the Nunavik Enrolment Review Committee: • Nunavik Inuit Beneficiaries List; and • List of Nunavik Inuit Beneficiaries Living Outside the Territory for Ten (10) or More Continuous Years. For publicly available information sources for this profile, see Additional Comments at the end of this document.
Custodian	On May 1, 2006, the Inuit beneficiaries register has been officially transferred from the Secretary General at the Québec Ministry of Health and Social Services (MSSS) to the Nunavik Enrolment Office, and the complete transition is foreseen to be terminated for December 2010. As of May 1 2006, new Inuit eligibility criteria and enrolment procedures took effect, as outlined in Section 3A of the Complementary Agreement No. 18 (C.A. 18) to the James Bay and Northern Quebec Agreement (JBNQA)
	Mandate of Custodian: The Nunavik Enrolment Office, under the authority of the Makivik Corporation (Makivik) Board of Directors, became entrusted with the maintenance and up-dating of the Nunavik Inuit Beneficiaries Register in accordance with the decisions of the Community Enrolment Committees and the Nunavik Enrolment Review Committee. The Registrar, who is the authority figure for the Nunavik Enrolment Office, is collaborating with its officer(s) and agent(s) out of the Makivik Corporation's head office in Kuujjuaq to ensure the maintenance and publication of the Nunavik Inuit Beneficiaries Register and to perform other statutory and ancillary responsibilities.
Purpose	Principal decision(s) or activities that the information is intended for (in your words): Determine eligibility for Nunavik Inuit Beneficiary entitlements.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☒ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	Nunavik Inuit Beneficiaries enrolled to the Nunavik Inuit Beneficiaries Register are entitled to receive a Nunavik Inuit Beneficiary Card issued by the

I. DATABASE – Nunavik Inuit Beneficiaries Register

	Nunavik Enrolment Office. The Cards are formatted to provide protection from fraud and identity theft, and contain: digitized photograph, registration number, family and given names, gender, date of birth, community of affiliation, community of residence, beneficiary number, Inuit "N" number issued by Health Canada if applicable.
Status & Update	Database status Active | Database update frequency Select One Frequency of Updates:
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Month/year of latest available ethno-cultural identifiers: 2011
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Community level
	Select One
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Makivik Corporation and its subsidiary companies, Nunavik Regional Board of Health and Social Services, Quebec Government, Health Canada (FNIHB, for out of territory beneficiaries who qualify for NIHB)
	Database also used by users external to Custodian
Populations	Population groups included in this database – Beneficiaries of the James Bay and Northern Quebec Land Claims Agreement
	Population Coverage - % of population targeted by the database that has been captured: N/A
	Alternatively, sample with weights? No. If yes, sample size N/A
Records	Total # of records in database: Approximately 10,000 people live in Nunavik, 9,045 of who are Inuit beneficiaries of the JBNQA. | Annual number of records collected/updated:
Contact/ Questions	Support Organization Makivik Corporation, Nunavik Enrolment Office Title of person in support role: The Registrar Name: Phone: (819) 964-2925 E-mail: nunavikenrolmentoffice@makivik.org
Web site	http://www.makivik.org/signature-of-james-bay-and-northern-quebec-complementary-agreement/ http://www.jepersevere.com/testmakivik/wp-content/uploads/2011/01/01-Regional-Guidel

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE	
Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): As of May 1st 2006, a person is entitled to be enrolled as a Nunavik Inuk beneficiary and to invoke the rights and privileges of the JBNQA if that person: (a) is alive; and (b) is a Canadian citizen; and (c) is an Inuk, as determined in accordance with Inuit customs and traditions; and (d) identifies himself/herself as an Inuk; and (e) is associated with an Inuit community through family, residential, historical, cultural or social connections with such a community; and (f) is not enrolled under another land claims agreement in Canada, unless it is an agreement related to the Nunavik Inuit rights, including those agreements that may be related to the Nunavik Marine Region surrounding Québec, to Labrador or to the Labrador offshore area; and (g) has his/her residence established or re-established in the Territory; or (h) has his/her residence established outside the Territory for less than ten (10 continuous years; or (i) has established his/her residence outside the territory during ten (10) or more years for purposes related to education, health or employment with an organization whose mandate is to promote the welfare of Inuit. An Inuit Beneficiary who has maintained his/her residence outside the Nunavik territory for 10 or more consecutive years is not entitled to exercise rights or receive benefits as a Nunavik Inuit Beneficiary, and his/her name is transferred to the List of Inuit Beneficiaries Living Outside the Territory for Ten (10) or More Continuous Years. The rights and privileges of the JNQA are suspended until the residency requirement is fulfilled. Such list is sometimes referred to as the Inactive List. In the meantime, all applicable federal and provincial government programs and funding made available to aboriginals and Inuit can be accessed by “inactive” Inuit beneficiaries. http://174.37.171.97/~makivik/wp-content/uploads/2011/02/Form-A-New-Enrolment-adult-Eng.pdf:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



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Société Makivik
Makivik Corporation

Nunavik Enrolment Office
P.O. Box 179
Kuujjuaq, Nunavik (Quebec) J0M 1C0
Tel: (819) 964-2925 Fax: (819) 964-0458
Website: www.makivik.org

Form A
Enrolment Nunavik Inuit Beneficiary Application Form
(Adult)

Nunavik Enrolment Office established under the authority of the Makivik Board of Directors is responsible to maintain the Nunavik Inuit Beneficiaries Register

Section A **IDENTIFICATION OF THE APPLICANT** **Page 1/2**

Applicant Family Name	Applicant Middle name	Applicant Given name(s)	☐ Female ☐ Male
Date of Birth (yy/mm/dd)	Place of Birth	Community Affiliation	Community of Residence
Home Tel.:			
Work Tel:			
Address of Residence	City	Province/Territory	Postal Code
Beneficiary No	Social Insurance No.	Health Care Card No.	Relationship to the person concerned ☐ Person Concerned ☐ Other (specify)

Section B **INFORMATION OF THE PERSON CONCERNED**

Family Name	Middle name	Given name(s)	☐ Female ☐ Male	
Date of Birth (yy/mm/dd)	Place of Birth	Home Phone No. Work Phone No.		
Address of Residence	City	Province/Territory	Postal Code	Total Years of Residence "Outside Territory" (if applicable)
Community of Residence	Community Affiliation	Social Insurance No.	Health Care Card No.	"N" Number Health Canada (if Applicable)

Section C **MARITAL STATUS OF THE PERSON CONCERNED**

Marital Status ☐ Single ☐ Married ☐ Common Law ☐ Separated ☐ Divorced ☐ Widow

Date of Event (yy/mm/dd)

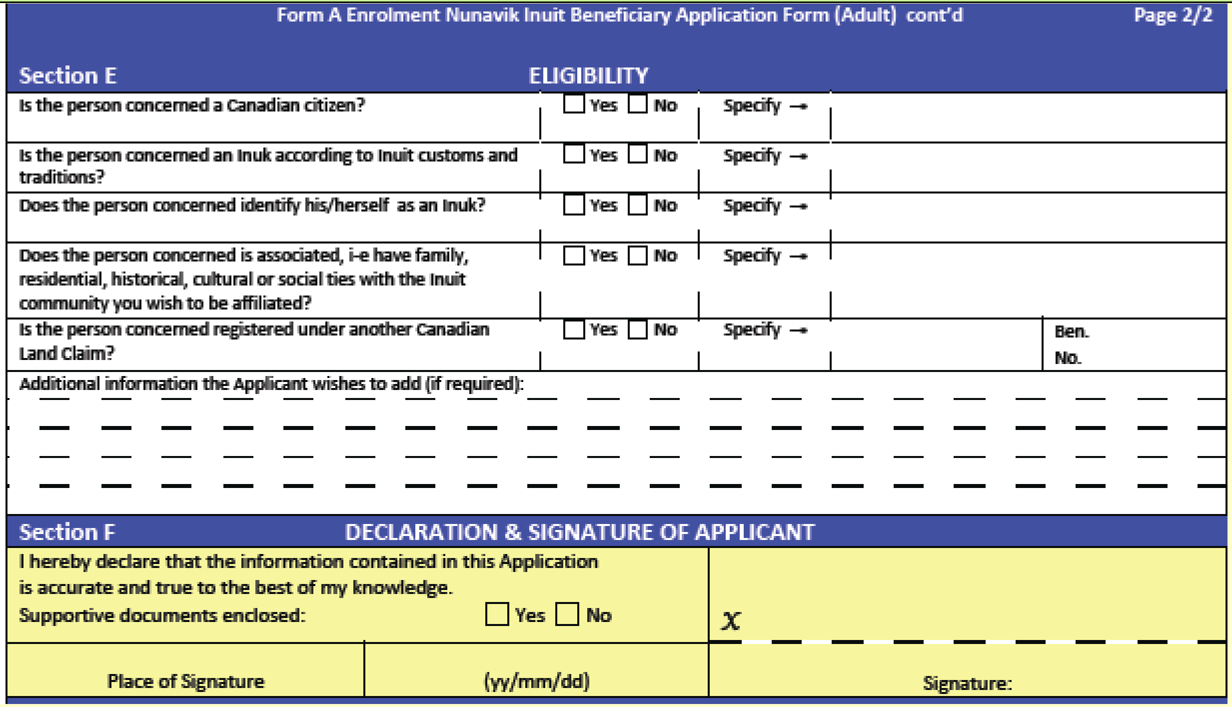
Family Name of Consort	Given Name(s)	
Date of Birth of Consort (yy/mm/dd)	Beneficiary No. Consort	SIN No. Consort

Section D **PARENTS OF THE PERSON CONCERNED**

Name of Father	Given name(s) of Father	Date of Birth (yy/mm/dd)	Ben. No.
Maiden Name of Mother	Given name(s) of Mother	Date of Birth (yy/mm/dd)	Ben. No.

Nunavik Enrolment Office
Form A / June 2010 (2 Pages)

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Form A Enrolment Nunavik Inuit Beneficiary Application Form (Adult) cont'd — Page 2/2

Section E — ELIGIBILITY

Is the person concerned a Canadian citizen?	☐ Yes ☐ No	Specify →		
Is the person concerned an Inuk according to Inuit customs and traditions?	☐ Yes ☐ No	Specify →		
Does the person concerned identify his/herself as an Inuk?	☐ Yes ☐ No	Specify →		
Does the person concerned is associated, i-e have family, residential, historical, cultural or social ties with the Inuit community you wish to be affiliated?	☐ Yes ☐ No	Specify →		
Is the person concerned registered under another Canadian Land Claim?	☐ Yes ☐ No	Specify →		Ben. No.

Additional information the Applicant wishes to add (if required):

Section F — DECLARATION & SIGNATURE OF APPLICANT

I hereby declare that the information contained in this Application is accurate and true to the best of my knowledge.

Supportive documents enclosed: ☐ Yes ☐ No

x

Place of Signature	(yy/mm/dd)	Signature:

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen: Pursuant to the requests made during consultations regarding eligibility, the criteria and enrolment procedures of the new regime grant local discretion to the Community Enrolment Committees to define and decide on eligibility of applicants under the provisions of C.A. 18. Nevertheless, considering the demand presented at the 2000 Makivik AGM to have common policies and guidelines produced to assist the work of the Community Enrolment Committees, proposed procedures, operations and actions concerning the enrolment of Inuit beneficiaries under the new Section 3A of the JBNQA are hereby presented as Policies and Guidelines guided by the following principles:

- Nunavik Inuit are best able to define who is an Inuk and who is therefore entitled to be enrolled under the JBNQA, and;
- Nunavik Inuit are to be recognized according to their own understanding of themselves, of their culture and traditions; and;
- The determination and decision process of who is an Inuk for the purposes of the JBNQA is to be just and equitable.

Ethno-cultural identity question(s) has been tested Select One
Test report re question design is available Select One
Name/citation for test report:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: See comments under "Question Design", which affirm that Nunavik Inuit are best able to define who is Inuk, and that Nunavik Inuit are to be recognized according to their own understanding of themselves, of their culture and traditions.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Test /pilot/ evaluation report is available Title/ citation for report:	Select One Select One
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality (optional)	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	The information provided on the Application for a Nunavik Inuit Beneficiary Card with Photo is protected under the provisions of the Privacy Act and is collected by the Nunavik Enrolment Office strictly for the purpose of issuing a Nunavik Inuit Beneficiary Card. The information contained in the Nunavik Inuit Beneficiary Register is managed by the Nunavik Enrolment Office and is subject to the Federal and Provincial laws concerning privacy of information. Consultation of the Register by the general public is possible without charge in person at the head office of the Nunavik Enrolment Office, subject to the appropriate laws on privacy. A free copy of the Register is also supplied annually to the Governments of Quebec and Canada as part of the agreed conditions of C.A. 18. Any other request to access the Nunavik Inuit Beneficiary Register shall be made in writing to the Nunavik Enrolment Office using the Access to nominative information of the Nunavik Inuit Beneficiaries Register Application Form (Form J). All requests must be specific about the information being requested and the time frame involved. Nunavik Enrolment Office may refuse to disclose personal information as requested by an applicant.
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☒ Collector of data ☒ Custodian ☒ Analyst ☒ User for decisions
	"Enrolment Program for Nunavik Inuit Beneficiaries of the James Bay and Northern Québec Agreement, Policies And Guidelines, June 1, 2010" provides full details of the process to develop and implement the policies and guidelines for the Enrolment Program for Nunavik Inuit Beneficiaries.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Select One Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)

IV. DATA USE & REPORTING

Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Inuit "N" Number for Nunavik Inuit Not Normally Resident of the Nunavik Territory Nunavik Inuit normally residing outside the Nunavik Territory are serviced by Health Canada for health considerations (Section 15.0.10 JBNQA). They access Non-Insured Health Benefits (NIHB) provided by Health Canada, inclusive of prescription drugs, over-the-counter medication, medical supplies and equipment, short-term crisis counseling, dental care, vision care, medical transportation, etc. They have to apply to Health Canada to obtain a client identification number which begins with the letter "N" and is followed by 8 digits. In order to obtain a "N" number, Nunavik Inuit must contact Health Canada (Québec region). Qualifications: As part of the Programs devolved to Aboriginals of Canada, Health Canada will issue an "N" number only to individuals of Inuit ancestries listed as "out of territory" or "OOT" in the Nunavik Inuit Beneficiaries Register. BENEFITS PROGRAMS PROVIDED TO NUNAVIK INUIT BENEFICIARIES - BENEFICIARIES RESIDING WITHIN NUNAVIK TERRITORY: Education programs (Kativik School Board), Health Programs (Tlattavik Health Centre Hospital (Kuujjuaq), Inuulittsivik Health Centre Hospital (Puvirnituq), Nunavik Regional Health Board & Social Services, Employment Programs (Kativik Regional Development Council), Membership & Voting Rights (Makivik Corporation, Inuit Nunavik Landholding Corporation, Inuit Northern Villages), Financial Assistance for specific projects, Hunting, Trapping and Fishing Right, Education Programs and Post-Secondary Studies. Information in this profile based on the following sources: - Enrolment Program for Nunavik Inuit Beneficiaries of the James Bay and Northern Québec Agreement, Policies And Guidelines, June 1, 2010 http://www.jepersevere.com/testmakivik/wp-content/uploads/2011/01/01-Regional-Guidel; - Form A: Enrolment Nunavik Inuit Beneficiary Application Form (Adult); - Portail informationnel Santé et Services sociaux: Registre des autochtones Cris, Inuits et Naskapis; http://www.informa.msss.gouv.qc.ca - accessed November 2, 2011; - Bill 16: An Act to amend the Act respecting Cree, Inuit and Naskapi Native Persons and Other Legislative Provisions, Québec Official Publisher, 2006; - James Bay and Northern Québec Agreement, English test of the agreement, Complementary Agreement No 18; - Nunavik Inuit Land Claims Agreement Implementation Plan; http://www.aadnc-aandc.gc.ca/eng/ accessed November 2, 2011.

4.5.2 Register of Cree, Inuit and Naskapis

I. DATABASE – Register of Cree, Inuit and Naskapis (Registre des autochtones Cris, Inuits et Naskapis)	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☒ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YK ☐ NT ☐ NV ☐ Other
Description	The James Bay And Northern Quebec Agreement (JBNQA) was a land claim settlement, approved in 1975 by the Cree and Inuit of northern Quebec, and later slightly modified in 1978 by the North-eastern Quebec Agreement, through which Quebec's Naskapi First Nations joined the treaty. The agreement covered economic development and property issues in northern Quebec, as well as establishing a number of cultural, social and governmental institutions for First Nations and Inuit who are members of the communities involved in the treaties. The Register of aboriginal Cree, Inuit and Naskapis people (Registre des autochtones Cris, Inuits et Naskapis) supports the implementation of the Agreement. The Register has three components: 1. The Cree Registry (Registre des autochtones Cris): it has personal information about ~ 10,000 Cree beneficiaries of the JBNQA. The Government of Québec collects this information via an application to meet its obligations under the JBNQA. The data are held by the Ministère de la Santé et des Services Sociaux (MSSS). 2. The Naskapis Registry (Registre des autochtones Naskapis): it has personal information about ~ 1,000 Naskapis. The Government of Québec collects this information via an application to meet its obligations under the JBNQA. The data are held by the Ministère de la Santé et des Servicices Sociaux (MSSS) 3. The Nunavik Inuit Beneficiaries Register: it has personal information about ~ 10,000 Inuit. On May 1, 2006, the Inuit beneficiaries register has been officially transferred from the Secretary General at the Québec Ministry of Health and Social Services (MSSS) to the Nunavik Enrolment Office, and the complete transition is foreseen to be completed soon. As of May 1 2006, new Inuit eligibility criteria and enrolment procedures took effect, as outlined in Section 3A of the Complementary Agreement No. 18 (C.A. 18) to the James Bay and Northern Quebec Agreement (JBNQA). The Nunavik Inuit Beneficiaries Register is composed of the two (2) following lists, maintained and updated in accordance with the decisions of the Community Enrolment Committees and of the Nunavik Enrolment Review Committee: • Nunavik Inuit Beneficiaries List; and • List of Nunavik Inuit Beneficiaries Living Outside the Territory for Ten (10) or More Continuous Years. The Nunavik Inuit Beneficiaries Register is described in a separate Profile.
Custodian	For the Cree and Naskapis portion of the Register: the Québec Ministry of Health and Social Services (MSSS) For the Inuit portion of the Register: the Nunavik Enrolment Office at Makivik Corporation (MSSS is helping with the interim management and transition)
	Mandate of Custodian: Québec Ministry of Health and Social Services (MSSS): To maintain, improve and restore health and well-being of Québec residents by making integrated and high quality health and social services accessible, and contributing to the social and economic development of Québec. The Nunavik Enrolment Office, under the authority of the Makivik Corporation (Makivik) Board of Directors, became entrusted with the maintenance and up-dating of the Nunavik Inuit Beneficiaries Register in accordance with the decisions of the Community Enrolment Committees and the Nunavik Enrolment Review Committee. The Registrar, who is the authority figure for the Nunavik Enrolment Office, is collaborating with its officer(s) and agent(s) out of the Makivik Corporation's head office in Kuujjuaq to ensure the maintenance and publication of the Nunavik Inuit Beneficiaries Register and to perform other statutory and ancillary responsibilities.
Purpose	Principal decision(s) or activities that the information is intended for (in your words): Determine eligibility for Cree, Naskapis and Nunavik Inuit Beneficiary

I. DATABASE – Register of Cree, Inuit and Naskapis (Registre des autochtones Cris, Inuits et Naskapis)

	entitlements under the James Bay and Northern Québec Agreement. En règle générale, les informations contenues sur ce fichier sont nécessaires, entre autres, pour valider des données reliées aux allocations familiales, aux pensions de vieillesse, à l'assurance-hospitalisation, au recensement de la population autochtone, à la mise à jour des bénéficiaires de la Convention de la Baie James et du Nord québécois, pour fins d'étude, de statistiques, etc.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☒ funding & reimbursement ☒ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☐ population ☐ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☒ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☒ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	The information collected includes: name, date of birth, sex, place of residence, community of affiliation. The communities of affiliation include 16 Inuit communities, 9 Cree communities, and 1 Naskapis community. For purposes of Non-Insured Health Benefits, beneficiaries who live in one of the communities in the Treaty Area are covered by the Province; if they move outside the Treaty Area, they are covered by the Federal NIHB Program.
Status & Update	Database status Active
	Database update frequency Ongoing / on regular frequency Frequency of Updates: monthly
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): July 1, 1977 for Naskapis; November 15, 1974 for Cree and Inuit Month/year of latest available ethno-cultural identifiers: 2011
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Community of affiliation
	Postal Code
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - Québec Government, including - but not limited to - the Ministry of Health and Social Services, Makivik Corporation and its subsidiary companies, Nunavik Regional Board of Health and Social Services, Health Canada (FNIHB, for out of territory beneficiaries who qualify for NIHB)
	Database also used by users external to Custodian
Populations	Population groups included in this database – Beneficiaries of the James Bay and Northern Quebec Land Claims Agreement

I. DATABASE – Register of Cree, Inuit and Naskapis (Registre des autochtones Cris, Inuits et Naskapis)

	Population Coverage - % of population targeted by the database that has been captured: ~ 100% of beneficiaries under JBNQA	
	Alternatively, sample with weights? No. If yes, sample size % of population	
Records	Total # of records in database: ~ 21,000, including ~ 10,000 Inuit, ~ 10,000 Cree, and ~ 1,000 Naskapis Beneficiaries	Annual number of records collected/updated: Many, as name changes, new residency, etc. all have to be reflected on the records. 300 modifications/ month is not uncommon.
Contact/ Questions	Support Organization Ministère de la Santé et des Services sociaux Title of person in support role: Direction générale de la coordination, du financement, des immobilisations et du budget Name: Phone: E-mail:	
Web site	http://www.informa.msss.gouv.qc.ca	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): The provincial criteria for enrolment by Cree and Naskapis are different from those used to apply for registered status on the (federal) Indian Register that is maintained by Aboriginal Affairs and Northern Development Canada (AANDC). It is not known how this affects the number of Cree and Naskapis registrants, as the Ministry of Health and Social Services does not compare provincial and federal numbers. For Nunavik Inuit Beneficiaries identity questions, see Profile: Nunavik Inuit Beneficiaries Register. Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached
Question Design	Reason why the above question and/or identifier were chosen: For Nunavik Inuit Beneficiaries identity questions, see Profile: Nunavik Inuit Beneficiaries Register. For Cree and Naskapis: criteria were set as per the James Bay and Northern Québec Agreement.
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report:
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: See comments under "Question Design"
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One Test /pilot/ evaluation report is available Select One Title/ citation for report:
Data Linkage	<u>Potential</u>, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality (optional)	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Select One An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as
	☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional):
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:
	First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications:
	1. 2.
Evidence-informed	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions:

IV. DATA USE & REPORTING

Decisions	1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Responsibility for health and social services in Cree communities is the responsibility of the Cree Board of Health and Social Services of James Bay. In Nunavik, these services are provided by the Nunavik Regional Board of Health and Social Services (NRBHSS). For the purpose of health expense reimbursement and administration of beneficiary entitlements, health care providers have a list of beneficiaries to facilitate NIHB billing. Information in this profile based on the following sources: • Portail informationnel Santé et Services sociaux: Registre des autochtones Cris, Inuits et Naskapis; formulaire autochtone cris, formulaire autochtone naskapis; http://www.informa.msss.gouv.qc.ca - accessed November 2, 2011 • Naskapi Nation of Kawawachikamach, Annual Report 2009-2010; • Research on the health of Québec First Nations: an overview, 1986 to 2006; • Bill 16: An Act to amend the Act respecting Cree, Inuit and Naskapi Native Persons and Other Legislative Provisions, Québec Official Publisher, 2006; • James Bay and Northern Québec Agreement, English test of the agreement, Complementary Agreement No 18; • Enrolment Program for Nunavik Inuit Beneficiaries of the James Bay and Northern Québec Agreement: Policies and Guidelines, June 1, 2010; • Form A: Enrolment Nunavik Inuit Beneficiary Application Form (Adult); • Nunavik Inuit Land Claims Agreement Implementation Plan; http://www.aadnc-aandc.gc.ca/eng/ accessed November 2, 2011.

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.6 NOVA SCOTIA

4.6.1 Nova Scotia - Colon Cancer Screening Registry

I. DATABASE – **Nova Scotia - Colon Cancer Screening Registry**				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☒ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	As part of the provincial roll-out of organized, population based colon cancer screening, Cancer Care Nova Scotia is developing a screening registry of all eligible Nova Scotians who are participating in the program. Participants in the colorectal screening program are encouraged to identify themselves as one of seven ethno-cultural groups in Nova Scotia: Acadian, African Canadian, Asian, First Nations, Immigrant - Other, Middle Eastern, White.			
Custodian	Cancer Care Nova Scotia			
	Mandate of Custodian: To reduce the effects of cancer on individuals and families through research, prevention and screening, and lessen the fear of cancer through education and information.			
Purpose	To learn, over time, how colon cancer affects people of various cultural/ ethnic communities. Evidence suggests that certain communities, e.g. individuals of African heritage, are at increased risk for developing colon cancer. These specific categories have been selected based on the Nova Scotia cultural competence guidelines and in consultation with other government organizations.			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☒ performance mgmt. & accountability	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy	☒ Service Delivery ☒ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☐ Inuit/Inuk	☐ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates:		
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98):	Month/year of latest available ethno-cultural identifiers:		
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One			
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify			
	Postal Code			

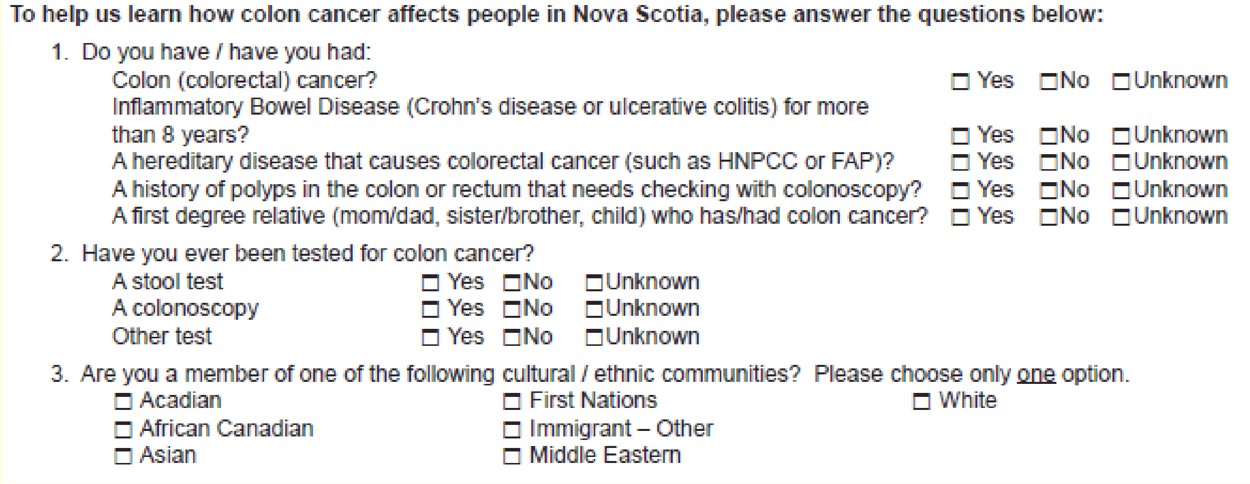
I. DATABASE – Nova Scotia - Colon Cancer Screening Registry

Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease	
Users	Primary users of this database - Cancer Care Nova Scotia: staff of the Prevention and Screening program; aggregate data are also used with/ by CCNS Diverse Communities Coordinator, clinicians (e.g. primary care physicians) and health and governance representatives of ethno-cultural communities.	
	Only users internal to Custodian use the database	
Populations	Population groups included in this database – ~ 250,000 colon cancer screening eligible Nova Scotians who are enrolled with the provincial health insurance program (MSI database) and are 50 - 74 years of age.	
	Population Coverage - % of population targeted by the database that has been captured: It is too early to answer this question definitively. The colorectal screening program started to roll-out in March 2009 across Nova Scotia's nine District Health Authorities, with the last DHA - which has 40% of provincial population - completing the first roll-out wave in 2011.	
	Alternatively, sample with weights? No. If yes, sample size % of population	
Records	Total # of records in database: At this early point in time of the provincial roll-out, 32% of the target audience has successfully completed a colorectal cancer screening test. No analysis has been done yet on the response rate to the ethno-cultural identity question.	Annual number of records collected/updated:
Contact/ Questions	Support Organization Cancer Care Nova Scotia Title of person in support role: Director, Cancer Prevention and Early Detection Name: Erika Nicholson Phone: 902-473-4622 E-mail: Erika.Nicholson@ccns.nshealth.ca	
Web site	www.cancercare.ns.ca	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): The ethno-cultural identity question is embedded into a 2-page participant form. This form provides instructions on how to participate in the Colon Cancer Prevention Program, who to contact for questions, requests personal information (name, HCN, DOB, address info) as well as name and address of medical care provider (family doctor, NP), and opt-in and opt-out information. An earlier version used the term "Caucasian", which was found to not always be understood, and hence replaced by the term "White".

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



To help us learn how colon cancer affects people in Nova Scotia, please answer the questions below:

1. Do you have / have you had:
   - Colon (colorectal) cancer? ☐ Yes ☐No ☐Unknown
   - Inflammatory Bowel Disease (Crohn's disease or ulcerative colitis) for more than 8 years? ☐ Yes ☐No ☐Unknown
   - A hereditary disease that causes colorectal cancer (such as HNPCC or FAP)? ☐ Yes ☐No ☐Unknown
   - A history of polyps in the colon or rectum that needs checking with colonoscopy? ☐ Yes ☐No ☐Unknown
   - A first degree relative (mom/dad, sister/brother, child) who has/had colon cancer? ☐ Yes ☐No ☐Unknown
2. Have you ever been tested for colon cancer?
   - A stool test ☐ Yes ☐No ☐Unknown
   - A colonoscopy ☐ Yes ☐No ☐Unknown
   - Other test ☐ Yes ☐No ☐Unknown
3. Are you a member of one of the following cultural / ethnic communities? Please choose only one option.
   - ☐ Acadian
   - ☐ African Canadian
   - ☐ Asian
   - ☐ First Nations
   - ☐ Immigrant – Other
   - ☐ Middle Eastern
   - ☐ White

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier were chosen: Evidence suggests that certain communities are at increased risk for colon cancer. Also, Nova Scotia government cultural competency guidelines identify the ethno-cultural communities in the above question; their inclusion was confirmed through consultation with government and community stakeholders.

Ethno-cultural identity question(s) has been tested Select One
Test report re question design is available Select One
Name/citation for test report:

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: This approach is noteworthy in a number of regards: 1) it uses a Direct Mail approach using the provincial health insurance database (which itself contains no ethno-cultural identifiers); 2) it asks people to self-identify at a point in time when they are - for the most part - still unaffected by cancer, i.e. at the prevention/ screening stage, and 3) it asks people to identify along seven selected dimensions of ethno-cultural communities that are relevant to Nova Scotia, including - but not limited to - First Nations. The latter fits with Cancer Care Nova Scotia's strategic choice to invest in outreach to diverse communities, patient navigation, and applying a cultural competency lens to e.g. practice guidelines.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No
Test /pilot/ evaluation report is available No
Title/ citation for report:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Linkage

Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1.

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

Data Quality

Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
A systematic approach to evaluating the quality of ethno-cultural identification data is in place	No
Data quality indicators that are used: Please specify	
Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No

Title/citation for test/pilot/quality evaluation report:

All staff have received cultural competency training. CCNS has not yet run analysis on the completeness of the ethno-cultural data, as the priority is the roll-out of the program, and overall participation in the screening test. Qualitatively, it is noted that there have been no phone calls from residents regarding the ethno-cultural question. The majority of client calls are with questions about how to do the screening test.

Data Cost

This approach replaces a more costly way to collect ethno-cultural identifiers Select One

Capacity

The custodian plans to keep collecting the ethno-cultural identifiers Yes
Barriers - if any – to ongoing collection of ethno-cultural identifiers:

III. DATA ACCESS

Privacy Constraints

A full Privacy Impact Assessment (PIA) has been developed and submitted to the Department of Health and Wellness, and is currently under review.

A Privacy Impact Assessment has been done for this database Yes

Information has been used for secondary purposes No
If yes, examples of secondary data use:

First Nations, Inuit, and/or Métis Engagement

First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes
An MOU or formal agreement governing development and/or use of the database is in place No
First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as

☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions

The initiative to include an ethno-cultural question in the colon cancer screening kit was directly influenced by discussions with ethno-cultural communities and their desire to understand the burden of cancer on their communities better. Nova Scotia's cultural competency guidelines specify a number of these communities. The actual approach was developed in consultation with diverse community resources at CCNS and NS government, as well as representatives of the communities involved.

OCAP

The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:

First Nations OCAP principles No	Inuit Land Claims research protocols Not Applicable	Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1. It is too early for data products: the first wave of the provincial roll-out is completing with the 9th and largest DHA in 2011.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions No Examples of evidence-informed decisions: 1. While not a direct result of this project, CCNS has worked with the Tui'kn Partnership (Mi'kmaq communities on Cape Breton Island) on prevention and screening education materials that are specific to these communities.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use No
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	The philosophy and approach applied to ethno-cultural identification in the Nova Scotia Colon Cancer Screening Registry is in synergy with 1) Nova Scotia's work towards promoting cultural competence in the delivery of provincial health care, and 2) The development and application of a cultural competence assessment tool for provincial program clinical guidelines. In other words, this initiative is not undertaken in isolation, but part of a deliberate provincial government focus. Ad 1): Nova Scotia’s Diversity and Social Inclusion (DSI) Initiative was a three-year project (2003 – 2006) with two main goals: • To lead in raising awareness of diversity and social inclusion issues in Primary Healthcare. • To consult with stakeholders including diverse populations to develop guidelines and policies. The DSI Initiative resulted in recommendations for culturally inclusive policies and Cultural Competence Guidelines for the Delivery of Primary Healthcare in Nova Scotia (2006). These are the first provincial guidelines for cultural competence in primary healthcare in Canada. The Guidelines state, among others, that "Cultural competence can work to reduce disparities in health services, address inequitable access to primary healthcare and respectfully respond to the diversity of Nova Scotians (race, ethnicity, language, sex, sexual orientation, gender identity, (dis)ability, spirituality, age, geography, literacy, education, income, etc.) 1. Nova Scotia DHAs, CHBs, the IWK, and primary healthcare organizations should ensure that their staff provide to Nova Scotia patients/consumers, primary healthcare that is respectfully delivered and responsive to cultural health beliefs, practices, lived experiences and linguistic differences in Nova Scotia. 2. The Nova Scotia Department of Health and Wellness, DHAs, CHBs, the IWK, and primary healthcare organizations should work collaboratively with culturally diverse populations, including but not limited to: First Nations, African Canadians, Acadians, Francophones and immigrant communities, to

IV. DATA USE & REPORTING

	design targeted, accessible and effective health initiatives in all aspects of primary healthcare. 3. The Nova Scotia Department of Health and Wellness, DHAs, CHBs, the IWK, and academic institutions should collaborate to devise and implement strategies for the recruitment, retention, and promotion of diverse health staff, providers and leaders at all levels. For a full description, see "Cultural Competence Guidelines for the Delivery of Primary Healthcare in Nova Scotia", July 2008, available from the Nova Scotia Department of Health and Wellness. Ad 2): The Cultural Competence Assessment Tool includes a list of opportunities where culture in its broadest interpretation can be embedded into the process, content, and outcomes of guideline development. Also included is a reporting form where observations and recommendations can be made explicit and shared among Provincial Program team members. To inform the development of the tool, a search for examples of cultural competence assessment in clinical guidelines was conducted nationally and in the United States, Scotland, New Zealand, Australia, and England. Key elements of the tool, including questions and the reporting format, are based on the findings of this search. A sample tool was first developed, applied, shared, and then further refined for ease of use. For a full description, see " Cultural Competence Assessment Tool for Clinical Guideline Development", September 2009, Revised January 2011, Endorsed by The Program Delivery Group, Nova Scotia Department of Health and Wellness, March 3, 2010.

4.6.2 Unama’ki Client Registry & Data Linkage Model

I.	**DATABASE – Unama'ki Client Registry and Data Linkage Model**
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☒ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NV ☐ Other Cape Breton
Description	The Unama'ki Client Registry (UCR) is an anonymous electronic registry of community members from the five Unama'ki (Cape Breton) First Nations (Eskasoni, Membertou, Potlotek, Wagmatcook and Waycobah). Members were identified using Indian Registry System data from Aboriginal Affairs and Northern Development Canada's (AANDC) Indian Registry System, and demographic data from EMRs used at the 5 First Nations' health centres. A provincially recognized identifier, the NS Health Card number, was added to the UCR to allow linkage with provincial health data sources. The data linkage model enables First Nations' health information to be pulled from administrative data and clinical registries for the purposes of generating health status reports for the 5 First Nations.
Custodian	Access to the Unama'ki Client Registry is controlled by an Unama'ki Data Access Committee. The committee is comprised of representatives from each of the 5 First Nations and the Nova Scotia Department of Health and Wellness. Any proposed use of the UCR for research purposes must also be approved by the First Nation Chiefs and by Mi'kmaq Ethics Watch. Access to health indicator reports generated from the UCR is controlled by the First Nations.
	Mandate of Custodian: The five Cape Breton First Nations are responsible for delivering a wide range of community-based health services (for example: health promotion, disease prevention, primary care, home care, etc.). The 5 Bands are working together to achieve health status and outcomes that are equal to, or better than, the overall Canadian population. This partnership is referred to as the "Tui'kn Partnership". Nova Scotia Department of Health and Wellness provides better health care for Nova Scotians and their families – by offering programs and services that protect and promote health, and treat illness. The mission of NSDHW is to empower individuals, families, partners, and communities to promote, improve and maintain the health of Nova Scotians.
Purpose	Information is being used to improve health services; measure the impacts of health programs; develop community health plans that are based on evidence; monitor the health of the Unama'ki population, and to carry out research.
	☒ Public Health & Surveillance ☒ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☒ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☒ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	Comments (Optional)
Status & Update	Database status Active
	Database update frequency Ongoing / on regular frequency Frequency of Updates: annual
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 2011
	Month/year of latest available ethno-cultural identifiers: 2011

I. DATABASE – Unama'ki Client Registry and Data Linkage Model

Level of Detail	1. Individual Record 2. If Individual Record was selected: Not identifiable 3. If Not identifiable was selected: Reversible
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Band level
	Postal Code
Service Domain	☒ Acute Care ☒ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☒ Primary Care ☒ Drugs ☒ Cancer ☒ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Mi'kmaq governance, health planning and service delivery.
	Database also used by users external to Custodian
Populations	Population groups included in this database – 5 Cape Breton Mi'kmaq First Nations with a combined registered population of ~ 7600 people.
	Population Coverage - % of population targeted by the database that has been captured: Estimated to be 100% of target population although some classification error may exist.
	Alternatively, sample with weights? No. If yes, sample size % Of population
Records	Total # of records in database: 9888 | Annual number of records collected/updated:
Contact/ Questions	Support Organization Tui'kn Partnership Title of person in support role: Project Manager Name: Stacey Lewis Phone: 902-564-6466 ext. 2820 E-mail: staceylewis@membertou.ca
Web site	www.tuikn.ca

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Not applicable: the registry links data from the Indian Registry System, EMR demographic data and provincial health card number registry.
Question Design	Reason why the above question and/or identifier was chosen: Please describe
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report:
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Access to accurate, timely and reliable information on chronic diseases is a challenge everywhere but nowhere more so than with First Nations people. This lack of information has hampered the ability of communities, health agencies, and governments at all levels to measure change and respond effectively to the health needs of First Nations people. The UCR provides the means to identify and analyze health status and health care utilization trends in First Nations populations and, where appropriate, compare findings to those in the overall population. The Unama'ki Client Registry (UCR) is the first of its kind in Canada. It is a unique registry combining First Nations, federal and provincial government data to allow extraction of administrative data from provincial systems for use by First Nations in their own health planning.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Establishing the UCR required partners to work through a myriad of complex inter-jurisdictional privacy, governance and technical issues. The UCR is an important innovation in that it arose from a data sharing agreement between partners who had no precedent for such sharing and, indeed, where there was no previous sharing precedent in Canada. Local capacity to access and use reliable health data has been improved through 1) new health indicator reports, 2) development of a web reporting tool, and 3) training for staff in the areas of data analysis, interpretation and reporting.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Yes Test /pilot/ evaluation report is available Yes Title/ citation for report: Creation of the Unama'ki Client Registry	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes
	Title/citation for test/pilot/quality evaluation report: Creation of the Unama'ki Client Registry	
	Evaluation of data quality was point in time. The UCR creation process has been re-engineered based on some of the lessons learned from the initial effort. The data flow has been simplified by reducing the number of hand-off points and centralizing the data linkage process at Medavie. A major benefit of the revised data flow is that at least part of the match could proceed with deterministic linkage. It is anticipated that the changes will make the data flow and linkage process less prone to error, improve the quality of the data matches (matching the data of individual community members from the three sources of data) and ultimately save time and reduce costs. Before implementing the revised data flow, our Client Registry PIA will need to be updated and submitted to NSDHW for review and approval. Adjustments and improvements to the data flow model will be made as the linkage process proceeds. This will facilitate the maximum possible efficiency, effectiveness, and match success rate. The data flow model will be reviewed at least annually and adjusted accordingly. An UCR Technical Working Group has been established to provide expert technical advice on the development and maintenance of the Unama’ki Client Registry. Specifically, the Technical Working Group will advise on, and oversee, the match process; make recommendations to the Unama’ki communities on how the UCR creation process can be re-engineered based on lessons learned from each iteration of the UCR; identify data quality issues and advise on ways to resolve them. The experience of developing the Unama’ki client registry also highlights the importance of client registries developed at the community level (in our case, the EMR registries). These are a most critical tool for registry development and strong quality control procedures are essential to ensure accuracy and completeness. The communities are contemplating the development of EMR registry data quality goals and standards, training, the introduction of automated data quality audit procedures, and EMR software programming changes in order to improve the overall accuracy and completeness of the EMR client registry. Funding to support the PIA revisions and data quality activities mentioned above is an on-going challenge.	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Cost

This approach replaces a more costly way to collect ethno-cultural identifiers No
Comments on cost (optional)

Capacity

The custodian plans to keep collecting the ethno-cultural identifiers Yes
Barriers - if any – to ongoing collection of ethno-cultural identifiers: Cost of maintaining registry, data quality improvement, and PIA updates are an on-going challenge. Model is dependent on in-kind contributions of time and expertise from a number of partners.

III. DATA ACCESS

Privacy Constraints

A Data Sharing Committee, through an exhaustive process over a two year period, worked through the complex inter-jurisdictional privacy issues that were required. To accomplish this an extensive review of extremely complex multi-party and inter-jurisdictional privacy issues had to take place and a comprehensive PIA was completed. First Nations principles regarding Ownership, Control, Access, and Possession of information (OCAP) were respected to the fullest extent possible. The Unama'ki Bands largely control the Registry and its use. As well, the health centres have fostered a "privacy sensitive" culture within their organizations through privacy reviews, privacy training, and the development of a comprehensive privacy policy framework and procedures.

A Privacy Impact Assessment has been done for this database Yes

Information has been used for secondary purposes Select One
If yes, examples of secondary data use:

First Nations, Inuit, and/or Métis Engagement

First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes
An MOU or formal agreement governing development and/or use of the database is in place Yes
First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as

☒ Designer (e.g. of question) | ☒ Collector of data | ☒ Custodian | ☒ Analyst | ☒ User for decisions

Comments on the nature and/or outcome of engagement (optional): On June 17, 2011, Nova Scotia Health and Wellness Minister Maureen MacDonald joined the Mi'kmaq Chiefs from Cape Breton to sign the Unama'ki Client Registry Data Sharing Agreement. This confirmed Nova Scotia's unique relationship with the province's First Nations in recognizing First Nations' rights to share information at the level of government-to-government communications, with the associated information privacy rights. "An agreement like this is unprecedented in Canada, and speaks to our strong commitment to improving the health of First Nations individuals in Cape Breton and across the province," said Ms. MacDonald. "This is a significant achievement and an important step forward in enhancing our capacity to meet the health needs of our community members," said Chief Denny.

Since 2008, the Tui'kn partnership has been working closely with the province, AANDC, Dalhousie University, Medavie Blue Cross, Health Canada and the Public Health Agency to create the registry. "The government of Canada is pleased to be working with the province of Nova Scotia and Unama'ki First Nations to enhance sharing of health information among communities, health authorities and government," said Leona Aglukkaq, Minister of Health.

Local staff have been trained in various aspects of data collection and interpretation. This capacity building is central to the overall strategy to improve the quality of health planning, management and evaluation

OCAP

The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:

First Nations OCAP principles Yes | Inuit Land Claims research protocols Select One | Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Cancer Care Nova Scotia, Reproductive Care Program of Nova Scotia, Cardiovascular Health Nova Scotia and the Population Health Research Unit at Dalhousie University are producing reports for the Tui'kn partnership to help plan the future health care of the Mi'kmaq in Cape Breton. 2. Tui'kn has developed new health reporting partnerships, for example: - Dalhousie Faculty of Medicine (diabetes surveillance system, analysis of mental health trends) - University of Manitoba (web based reporting system).
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. using data to inform the development of community health plans; 2. using data to plan and evaluate chronic disease prevention and management services; for example, initiatives focused on hypertension monitoring and control
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Dissemination of the UCR model and process have taken place with news of the project passing by word of mouth to national organizations like Infoway and Health Canada. As a consequence, invited presentations have been made to a number of groups and organizations such as AFN, the Panorama project committee, Program Managers for e-Health at Health Canada, the Infoway Health Information Privacy group, etc. A number of presentations have also been delivered at national conferences. The Data Sharing Agreement , data access policies and procedures, data flow model, etc. have been requested and shared with a number of jurisdictions and informal discussions have taken place with other First Nations and provincial counterparts.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Comments (optional):
	Thoughts/advice on factors that would <u>Support</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Having "champions with the right connections" is key. Early on in the process, an Unama'ki Client Registry Data Sharing Committee (DSC) was established. This dedicated team was composed of the health clinic directors of the five First Nations bands in Cape Breton, Nova Scotia Department of Health and Wellness staff (DHW), personnel from several Provincial Programs (Cancer, Reproductive Care and Cardiovascular Health), Health Canada's First Nations and Inuit Health Branch, researchers at Dalhousie University, and District Health Authority representatives). This group was diverse in both its jurisdictional makeup and interests but the many points of view were absolutely critical to informing debate and balancing the interests between the parties. These partners all brought complementary "assets" to the process, including the political will between the governments of Nova Scotia and the five First Nations to recognize each other's rights with regard to privacy and control over information, and the willingness of the Federal Government (Health Canada and the Public Health Agency) to invest significant funds in the development of the registry and the relationships around it. In addition, an important factor appears to be access to skills and infrastructure support for the project, including transfer of skills to First Nations members. Advice to other jurisdictions contemplating similar data linkages: ☐ Take the time to build mutual understanding ☐ Political will is essential ☐ Be patient, persevere, remain optimistic ☐ Build a clear data flow model – spend the time required to get it right ☐ Map out a realistic timeline… then double it ☐ Engage those who can provide legal, policy and privacy expertise early in the process

IV. DATA USE & REPORTING

	Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Developing indicators for small populations presents a number of important challenges such as describing and comparing small populations, and the potential variability in the validity of indicators. Reports derived from UCR do not capture all health care utilization (e.g. utilization of community-based mental health services and traditional healing are not captured). Reports do not capture data on other determinants of health (e.g. income, education, environment); however, the potential exists to link the UCR with other "non-health" administrative data bases in order to get a more complete picture of population health.

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.7 NEWFOUNDLAND AND LABRADOR

4.7.1 Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement

I. DATABASE – Enrolment Register of Beneficiaries to the Labrador Inuit Land Claims Agreement

Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☒ NL ☐ YT ☐ NT ☐ NV ☒ Other Nunatsiavut
Description	The Labrador Inuit Land Claims Agreement (2005) set a precedent by including self-government provisions within the land claim. Nunatsiavut is the first of the Inuit regions in Canada to have achieved self-government. The Nunatsiavut Government is an Inuit regional government. Although Nunatsiavut remains part of Newfoundland and Labrador, the government has authority over many central governance areas including health, education, culture and language, justice and community matters. The Department of Health and Social Development (HSD) is responsible for the health and social development needs of Nunatsiavut beneficiaries. Since 2007, the Nunatsiavut Government prepares and maintains a register that contains the name of each individual who is determined to be a beneficiary of the Agreement. Prior to the LILCA, The Labrador Inuit Association administered applications for the Labrador Inuit. As a result, the Registry includes data going back 26 years, to 1985.
Custodian	The Office of the Registrar of Beneficiaries
	Mandate of Custodian: The Office of the Registrar of Beneficiaries in Nain is responsible for beneficiary registration and for maintaining a current Enrolment Register of Beneficiaries to the Labrador Inuit Land Claims Agreement. The Registrar's Office also provides support and coordination services for the Membership Committees and the Inuit Appeal Board to exercise their responsibilities for enrolment of beneficiaries.
Purpose	Principal decision(s) or activities that the information is intended for (in your words): It is crucial for the Nunatsiavut GovernmEmily Areyent to have an accurate, up-to-date register of beneficiaries to the LILCA. We need this data to prepare voters lists for elections; define and deliver Inuit specific programming; and negotiate financial agreements with the federal and provincial governments.

☐ Public Health & Surveillance	☐ Operating a Health Organization or System	☐ Research	☒ Service Delivery
☐ screening	☐ funding & reimbursement	☐ population	☒ enrolment/membership
☐ immunization	☐ transactions, e.g. drug dispensing	☐ clinical	☐ evaluation
☐ communicable disease	☐ capacity & utilization planning	☐ program/service	☐ equity
☐ other Specify	☐ performance mgmt. & accountability	☐ public policy	☐ patient navigation

Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☐ First Nation/North American Indian	☒ Inuit/Inuk	☐ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☒ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	Comments (optional):			

Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates: yearly After the Register is published under section 3.7.1, the Nunatsiavut Government shall: (a) update the Register at least once a year; and (b) give a copy of the updated Register to each of Canada, the Province and the Membership Committees.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1985	Month/year of latest available ethno-cultural identifiers: 2011

I. DATABASE – Enrolment Register of Beneficiaries to the Labrador Inuit Land Claims Agreement

Level of Detail	1. Select One 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Select One
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - The Government of Nunatsiavut and its departments, including the Health Services Department
	Database also used by users external to Custodian
Populations	Population groups included in this database – All eligible beneficiaries of the Labrador Inuit Land Claims Agreement
	Population Coverage - % of population targeted by the database that has been captured: ~ 100% of all eligible beneficiaries of the LILCA
	Alternatively, sample with weights? No. If yes, sample size % Of population
Records	Total # of records in database: As of October 4, 2011: 7,089 beneficiaries in total. 2,568 of these live in the Labrador Lands Claim Area, the balance live in other parts of Labrador (e.g. Happy Valley Goose Bay, Southern Labrador) and across Canada. Details at end of Profile. Annual number of records collected/updated:
Contact/ Questions	Support Organization Government of Nunatsiavut, Nunatsiavut Affairs Title of person in support role: Registrar of Beneficiaries Name: Don Dicker Sr. Phone: (709) 922-2942 x 251 E-mail: don_dicker@nunatsiavut.com
Web site	http://www.nunatsiavut.com

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Annex 1 to the Beneficiaries Enrolment Forms Amendment Regulations (2011) features a 15 page Application to be Enrolled as a Beneficiary of The Labrador Inuit Land Claims Agreement; cf. http://www.nunatsiavut.com/index.php/en/nunatsiavut-affairs/registrar-of-beneficiaries. The eligibility criteria are as follows: Note to those applying as Nunatsiavut Beneficiary, below is the Eligibility Criteria as stated in the Labrador Inuit Land Claims Agreement: PART 3.3 ELIGIBILITY CRITERIA 3.3.1 An individual is eligible to be enrolled on the Register if that individual meets the Criteria. 3.3.2 An individual shall be enrolled on the Register if, on the Effective Date, that individual is alive and is: (a) a Canadian citizen or a permanent resident of Canada under Federal Legislation; (b) an Inuk pursuant to Inuit customs and traditions and is of Inuit ancestry, or is a Kablunângajuk; and (c) either: (i) a Permanent resident of the Labrador Inuit Settlement Area; or (ii) a Permanent resident of a place outside the Labrador Inuit Settlement Area but is connected to the Labrador Inuit Settlement Area. 3.3.3 An individual who has at least one-quarter Inuit ancestry is eligible to be enrolled on the Register if that individual is a Canadian citizen or a

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	permanent resident of Canada under Federal Legislation despite anything in section 3.3.2 or 3.3.4 to the contrary. 3.3.4 Anyone who is born after the Effective Date who is a lineal descendant of someone who was enrolled or eligible to be enrolled on the Register under section 3.3.2 or 3.3.3 shall be enrolled on the Register if that individual is: (a) a Canadian citizen or a permanent resident of Canada under Federal Legislation; (b) an Inuk pursuant to Inuit customs and traditions and is of Inuit ancestry or is a Kablunângajuk under clause (a) of the definition of “Kablunângajuk”; and (c) either: (i) a Permanent Resident of the Labrador Inuit Settlement Area; or (ii) a Permanent Resident of a place outside of the Labrador Inuit Settlement Area but is connected to the Labrador Inuit Settlement Area. 3.3.5 Anyone who is not an Inuk or Kablunângajuk and who: (a) was adopted as a minor prior to the Effective Date by an individual who is eligible to be enrolled on the Register under section 3.3.2 or 3.3.3, or who would have been eligible to be enrolled under one of those sections if that individual had been alive on the Effective Date; or (b) is adopted as a minor by a Beneficiary after the Effective Date, is absolutely deemed to be a lineal descendant of his or her adoptive parents and to have the same ancestry that he or she would have had if he or she were a natural child of the adoptive parents. 3.3.6 No individual can be enrolled as a Beneficiary under the Agreement while that individual is enrolled under another Canadian Aboriginal Land Claims Agreement. 3.3.7 Anyone who is eligible to be enrolled under both the Agreement and another Canadian Aboriginal Land Claims Agreement may choose to be enrolled under the Agreement if that individual gives up his or her rights, benefits or privileges under the other agreement while enrolled under this Agreement. Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached
Question Design	Reason why the above question and/or identifier was chosen: The Nunatsiavut Government prepares and maintains a register that contains the name of each individual who is determined to be a beneficiary of the Agreement. From "Labrador Inuit Land Claims Agreement, Chapter 3, Eligibility and Enrolment", page 30-31: "Inuit" means all those members of the aboriginal people of Labrador, sometimes known as Eskimos, that has traditionally used and occupied and currently uses and occupies the lands, waters and sea ice of the Labrador Inuit Land Claims Area, or any Region. “Inuit” does not include beneficiaries of: (a) the “James Bay and Northern Québec Agreement”; (b) the “Inuvialuit Final Agreement”; or (c) the “Agreement between the Inuit of the Nunavut Settlement Area and Her Majesty the Queen in Right of Canada”; "Inuk" is the singular of Inuit; "Kablunângajuit" is the plural of Kablunângajuk; "Kablunângajuk" means an individual who is given that designation according to Inuit customs and traditions and who has: (a) Inuit ancestry; (b) no Inuit ancestry but who settled permanently in the Labrador Inuit Land Claims Area before 1940; or (c) no Inuit ancestry, but: (i) is a lineal descendant of an individual referred to in clause (b); and (ii) was born on or before November 30th, 1990;
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report:
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The registry provides names, residency, date of birth and gender of all the beneficiaries of the LILCA. The beneficiary number, which is used for e.g. NIHB reimbursement, can be linked to the provincial health insurance number (MCP number) from a technical feasibility point of view.
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One Test /pilot/ evaluation report is available Select One Title/ citation for report:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database:				
	A Privacy Impact Assessment has been done for this database Select One				
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:				
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as				
	☐ Designer (e.g. of question)	☐ Collector of data	☐ Custodian	☐ Analyst	☐ User for decisions
	The Labrador Inuit Land Claims Agreement, Chapter 3, Eligibility and Enrolment" describes the nature of the Registry, and was obviously developed by and with the Labrador Inuit Beneficiaries				
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:				
	First Nations OCAP principles Not Applicable	Inuit Land Claims research protocols Select One	Métis requirements Not Applicable		

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	The Nunatsiavut Department of Health & Social Development provides a range of programs and services to Nunatsiavut Beneficiaries including: ● Non-Insured Health Benefits ● Injury Prevention ● Addictions ● Communicable Disease Control ● Healthy Children Initiatives ● Home and Community Care ● Sexual Health ● Healthy Lifestyles ● Mental Wellness The Department of Health and Social Development (HSD) administers the NIHB on behalf of the First Nations, Inuit and Aboriginal Health Branch of Health Canada and has adopted Health Canada's policies that guide the benefits provided, standardization and evidence-based support. HSD has a regional office in Happy Valley-Goose Bay and seven community offices located in North West River, Happy Valley-Goose Bay, Rigolet, Postville, Makkovik, Hopedale and Nain. The regional level of HSD is responsible for oversight, policy development and program development and implementation. At the community level, HSD community teams work closely with Labrador-Grenfell Health to deliver health and social services in Nunatsiavut. Community Health Teams in all communities include a Public Health Nurse, Community Health Workers and Child Care Workers. Mental Health Teams have been also been created, with some communities sharing positions and/or receiving regularly scheduled services. HSD uses the Beneficiary Register regularly for planning and proposal development for health and social programs.

IV. DATA USE & REPORTING

Number of Beneficiaries registered with the Nunatsiavut Government, and where they live:

In the Land Claims Area:		Outside the Land Claims Area:	
Nain	1,151	Nunakatiget (Happy Valley Goose Bay, includes Mudlake, NL)	2008
Hopedale	588	Sivunivut (North West River, NL)	293
Postville	195	Canadian Constituency (Labrador West, Southern Labrador & the rest of Canada)	2,200
Makkovik	337		
Rigolet	297		

Total number of Beneficiaries as of October 04, 2011: 7,089

4.7.2 Newfoundland and Labrador Aboriginal Administrative Data Identifier

<table>
<tr><th colspan="5">I. DATABASE – Newfoundland and Labrador Aboriginal Administrative Data Identifier</th></tr>
<tr><td>Geography</td><td colspan="4">☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☒ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify</td></tr>
<tr><td>Description</td><td colspan="4">The need for an Aboriginal Data Identifier within health system has long been recognized. Current methodologies rely on postal codes to identify the records of individuals from communities whose populations are predominantly Aboriginal. This is inadequate for the following uses:
• Demographic analysis
• Health services utilization management
• Health services planning
• Health promotion and education
• Health services evaluation
• Health status indicator development and analysis
• Chronic disease surveillance
• Communicable disease surveillance
• Health research
• Funding requests
• Other uses (e.g. data quality, health human resource planning, etc.)
Following the successful conclusion of the regional Labrador Aboriginal Identifier Project, Newfoundland & Labrador (NL) participants concluded that identifying Aboriginal people in health data sets requires a provincial scope. Upon the request of the Department of Health and Community Services, a provincial working group was established in January 2010. It has been working towards a provincial data standard for Aboriginal identification within key health information systems, as well as a plan for implementation. As of November 2011, the proposed standard is being submitted to the Dept. of Health and Community Services, Government of Newfoundland and Labrador for approval, which will involve cross-ministerial review.</td></tr>
<tr><td rowspan="2">Custodian</td><td colspan="4">The project is at the stage of defining the data standard and supporting mechanisms, and an implementation approach for adopting the standard within key provincial health information systems.</td></tr>
<tr><td colspan="4">Mandate of Custodian: The project is at the design stage. Current thinking includes collection of the information for one provincial database and sharing of the identifier through data linkage to other provincial health databases.</td></tr>
<tr><td rowspan="2">Purpose</td><td colspan="4">Inclusion of an Aboriginal Administrative Data identifier in multiple regional and provincial health information systems would support setting and measuring outcomes and health indicators, and could be applied to designing appropriate programs and services for managing and improving health.</td></tr>
<tr><td>☒ Public Health & Surveillance
☐ screening
☐ immunization
☒ communicable disease
☒ other chronic disease</td><td>☒ Operating a Health Organization or System
☐ funding & reimbursement
☐ transactions, e.g. drug dispensing
☒ capacity & utilization planning
☒ performance mgmt. & accountability</td><td>☒ Research
☒ population
☒ clinical
☒ program/service
☒ public policy</td><td>☒ Service Delivery
☐ enrolment/membership
☒ evaluation
☒ equity
☒ patient navigation</td></tr>
</table>

I. DATABASE – Newfoundland and Labrador Aboriginal Administrative Data Identifier

Demographics	☒ Database includes demographic data ☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☒ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☒ Nunatsiavut
	☒ Métis ☐ On Métis register ☒ Other NunatuKavut (formerly, Labrador Métis)
	☒ Aboriginal ☒ Other a category for Aboriginal people who are not a member of 1 of 7 NL communities
	The specific identifiers being recommended for NL incorporate, and go beyond, the differentiation between First Nation, Inuit and Métis, to reflect the priorities of the NL Aboriginal communities. Therefore, the recommended taxonomy defines values for each of the 6 communities, as well as "Aboriginal, but not a member/beneficiary associated with one of the specified communities"; specifically, they are members/ beneficiaries of • Labrador Inuit Land Claim (Nunatsiavut) • Miawpukek First Nation • Mushuau Innu First Nation • NunatuKavut (formerly Labrador Métis Nation) • Qalipu Mi'kmaq First Nation • Sheshatshiu Innu First Nation • None of the above
Status & Update	Database status Inactive Database update frequency Ongoing / on regular frequency Frequency of Updates: TBD
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): N/A Month/year of latest available ethno-cultural identifiers: N/A
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☒ Other Community
	Postal Code
Service Domain	☒ Acute Care ☒ Emergency Care ☒ Complex Continuing Care ☒ Rehabilitation ☒ Mental Health/Addictions ☒ Palliative Care ☒ Long Term Care ☒ Home & Community Care ☒ Primary Care ☐ Drugs ☒ Cancer ☒ Diabetes ☒ Renal Dialysis ☒ Immunization ☒ Communicable Disease
Users	Primary users of this database - This standard may be adopted within regional and provincial information systems. De-identified data files and aggregate rep will be used by researchers and those involved with policy/program/service evaluation.
	Only users internal to Custodian use the database
Populations	Population groups included in this database – Newfoundland and Labrador's self-identified First Nation, Inuit and Labrador Métis people.
	Population Coverage - % of population targeted by the database that has been captured: The target is for the database to cover (close to) 100% of Aboriginal (and non-aboriginal) people in Newfoundland and Labrador.
	Alternatively, sample with weights? No. If yes, sample size % of population

I. DATABASE – Newfoundland and Labrador Aboriginal Administrative Data Identifier

Records	Total # of records in database: N/A	Annual number of records collected/updated:
Contact/ Questions	Support Organization Newfoundland and Labrador Centre for Health Information Title of person in support role: Director, Data Quality and Standards Name: Ann Vivian-Beresford Phone: (709) 752-6003 E-mail: ann.beresford@nlchi.nl.ca	
Web site	http://www.nlchi.nl.ca	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached
Question Design	Reason why the above question and/or identifier was chosen: Development of questions/ values for answers took into account the Aboriginal Administrative Data Standard whose development was led by the BC Ministry of Aboriginal Relations and Reconciliation for the purpose of implementing a provincial government data standard for the collection of data specific to Aboriginal persons. Then, in further discussions with the Newfoundland and Labrador stakeholders, it was decided to go beyond values for First Nations, Inuit and Métis, and create additional values for Community-level Aboriginal affiliations, e.g. a specific First Nation community. The emerging NL data standard also defines whether a person is a beneficiary of First Nations or Inuit (Nunatsiavut) treaty rights.
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report: No testing done yet at this point in development.
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: If the recommendations are accepted through the government review process, this would be the first time Newfoundland and Labrador will have designed an implementation plan for collecting ethno-cultural First Nations, Inuit and Métis identifiers that build on existing good practice, and incorporate community requirements. The resulting identifiers could be linked to other main health data holdings in Newfoundland and Labrador, including MCP Beneficiary Registration Database, Vital Event databases, Clinical Database Management System (hospital inpatient and day surgery data) and disease-specific data holdings such as the Cancer Registry. At this point in time, three options for implementation are being considered: a) embed the identifiers in the data collection processes everywhere; b) collect the identifiers once, and electronically link them - where feasible - to other health data sets; c) collect the identifiers where this is feasible, and share them electronically where it is not feasible. An example of Option b) under consideration is to collect the identifiers at the point of registration, or 5-yearly re-registration, for the provincial health insurance plan (MCP) - with a 2-digit code being embedded into the MCP card. This would give NL residents the opportunity to self-identify at five-yearly intervals; RHAs would be able to input the information into their local information systems. Through cross linkage of the MCP file with records in other provincial health databases, the identifier could be embedded within other systems.
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No Test /pilot/ evaluation report is available No Title/ citation for report: No testing done yet at this point in the development.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	No
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	No
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	No
	Data quality indicators that are used: N/A yet	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report: N/A	
	Upon approval, a detailed implementation plan will be developed.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Currently do not have a provincial ethno-cultural identifier.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Select One Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Part of the implementation plan would be the creation of a governance structure with appropriate data sharing agreements, in line with provincial and federal legislation .
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	This project is still at the design/ development stage. One of its main features has been broad and inclusive participation from provincial stakeholders and local Aboriginal communities.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One | Inuit Land Claims research protocols Select One | Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1. Indicators have not been adopted or implemented yet 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions No Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes The initiative has benefitted from a common interest, and collaborative work involving representation from the regional/local as well as provincial levels. The Provincial Working Group includes representation from the NL Centre for Health Information (the Centre), the Departments of Health and Community Services (including the Medical Care Plan (MCP), Aboriginal Liaison Office and Policy Development Division), Labrador and Aboriginal Affairs, and Government Services (Vital Statistics Division), Miawpukek First Nation, Qalipu Mi'kmaq First Nation, Mushuau Innu First Nation, Sheshatshiu Innu First Nation, NunatuKavut Community Council, and the Labrador Inuit Land Claim (Nunatsiavut Government). The provincial group is co-chaired by the Dept. of Health and Community Services and the Centre for Health Information. The cross-representation between the Labrador Advisory Committee and the Provincial Working Group enabled strong collaboration between the two groups from the outset. As part of the precursor project (Labrador Aboriginal Identifier Project), strong working relationships had been set up involving Labrador-Grenfell Health (LGH) in partnership with Nunatsiavut Department of Health and Social Development, NunatuKavut Community Council (formerly Labrador Métis Nation), Sheshatshiu Innu First Nation, the Mushuau Innu First Nation and the Department of Health and Community Services, Government of Newfoundland and Labrador. An Advisory Committee was formed with representation from all the Labrador partners in the LGH area and from the Newfoundland and Labrador Centre for Health Information (the Centre). The project has also benefitted from the expertise and support of Statistics Canada, Health Canada First Nations and Inuit Health E-Health, Newfoundland and Labrador Cancer Centre and the Provincial Epidemiologist. This inclusive approach involving local/regional as well as provincial health authorities, governance representatives at all levels and information experts has been a key component in shared learning, development of a common identifier approach, and capacity building towards future implementation.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Several learnings have emerged in the course of the past 2 - 3 years, including: 1. There is no need to reinvent the wheel: taking someone else's work, e.g. the questions used in Statistics Canada surveys, and the Aboriginal Administrative Data Standard developed in B.C., were obvious starting points. 2. Creating the right process and structure for provincial participation and collaboration is fundamental to success. In Newfoundland and Labrador, we are fortunate, partially because of the size of our population, to be able to get many of the key participants around the table in the same room and connect others by phone. Previous working relationships existed for many participants and facilitated the work of the group. Participation and support of the Aboriginal communities is critical to the validity of the standard and support for acceptance during implementation. Government support is also vital for successful adoption. 3. The health database world is not familiar to the majority of participants. Our experience suggests that upfront time invested in creating a baseline understanding re what health databases exist, where they reside, what they contain, who uses the data for what purpose, etc. is time well spent.

IV. DATA USE & REPORTING

	4. It is helpful to check assumptions. The Working Group commissioned a survey of all stakeholder groups and the four Health Authorities re the potential uses for an Aboriginal Identifier. This provided important validation of some key initial assumptions. 5. Beyond the immediate goal of creating consensus around a new data standard, the work in and around the Work Group is raising awareness of the potential of the data and its uses. 6. Provincial privacy legislation specific to personal health information is of great benefit as it provides clear guidance on the rules for data collection, use, and disclosure of identifiable information. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: 1. Upon undertaking the initial Labrador project, it was recognized that adding Aboriginal Identifiers to key data holdings requires a provincial initiative, not just a regional approach. The proposed standard contains a level of detail beyond that used by Stats Canada by identifying the specific Aboriginal communities to which individuals identify/belong. This will make the data more meaningful to all parties. 2. Most of the Newfoundland and Labrador's Aboriginal groups will easily "map to" a national First Nations, Inuit and Métis taxonomy. The exception being the Labrador Métis, which is a distinct group with a mix of Inuit and European ancestry.
Additional Comments	While NL is not yet ready to adopt the standard, there is support for the idea of leveraging existing processes and electronically link the data to facilitate implementation across databases where possible. This will reduce implementation costs, effort and time ultimately. Strict adherence to privacy legislation, sound information management policy and process is required to provide a comfort level to the population that the data will be collected, used and disclosed appropriately.

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.8 NORTHWEST TERRITORIES

4.8.1 Inuvialuit Regional Corporation Enrolment Registry

I. DATABASE – Inuvialuit Regional Corporation Enrolment Registry	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☒ NT ☐ NV ☒ Other Specify
Description	The origin of the Inuvialuit Corporate Group, composed of Inuvialuit Regional Corporation (IRC) and its subsidiary corporations, began with the signing of the Inuvialuit Final Agreement on June 5, 1984, between the Government of Canada and the Inuvialuit - Inuit of Canada's Western Arctic. The basic goals of the Inuvialuit Final Agreement (IFA) as expressed by the Inuvialuit and recognized by Canada are to: • Preserve Inuvialuit cultural identity and values within a changing northern society. • Enable Inuvialuit to be equal and meaningful participants in the northern and national economy and society. • Protect and preserve the Arctic wildlife, environment and biological productivity. Enrolment is the process to be recognized as a beneficiary of the Inuvialuit Final Agreement (IFA).
Custodian	The process is administered by the Enrolment Registrar and Enrolment Committee of the IRC.
	Mandate of Custodian: IRC was established with the overall responsibility of managing the affairs of the Settlement as outlined in the IFA. Its mandate is to continually improve the economic, social and cultural well-being of the Inuvialuit through implementation of the IFA and by all other available means.
Purpose	A person who is on the Inuit Enrolment List is entitled to benefit from the NLCA so long as he or she is alive.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☒ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	To be recognized as a beneficiary, a person has to be 18 years old, a Canadian citizen, and fulfill the objective criteria set forth in the IFA and IRC's By-law #2.
Status & Update	Database status Active
	Database update frequency Ongoing / on regular frequency Frequency of Updates: yearly The Enrolment Committee reviews applications once a year in the month of April. Applicants who fulfill the objective criteria for enrolment are enrolled. Applicants who are denied are sent a letter explaining the reasons for the denial.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Month/year of latest available ethno-cultural identifiers: 2011
Level of Detail	1. Select One 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One

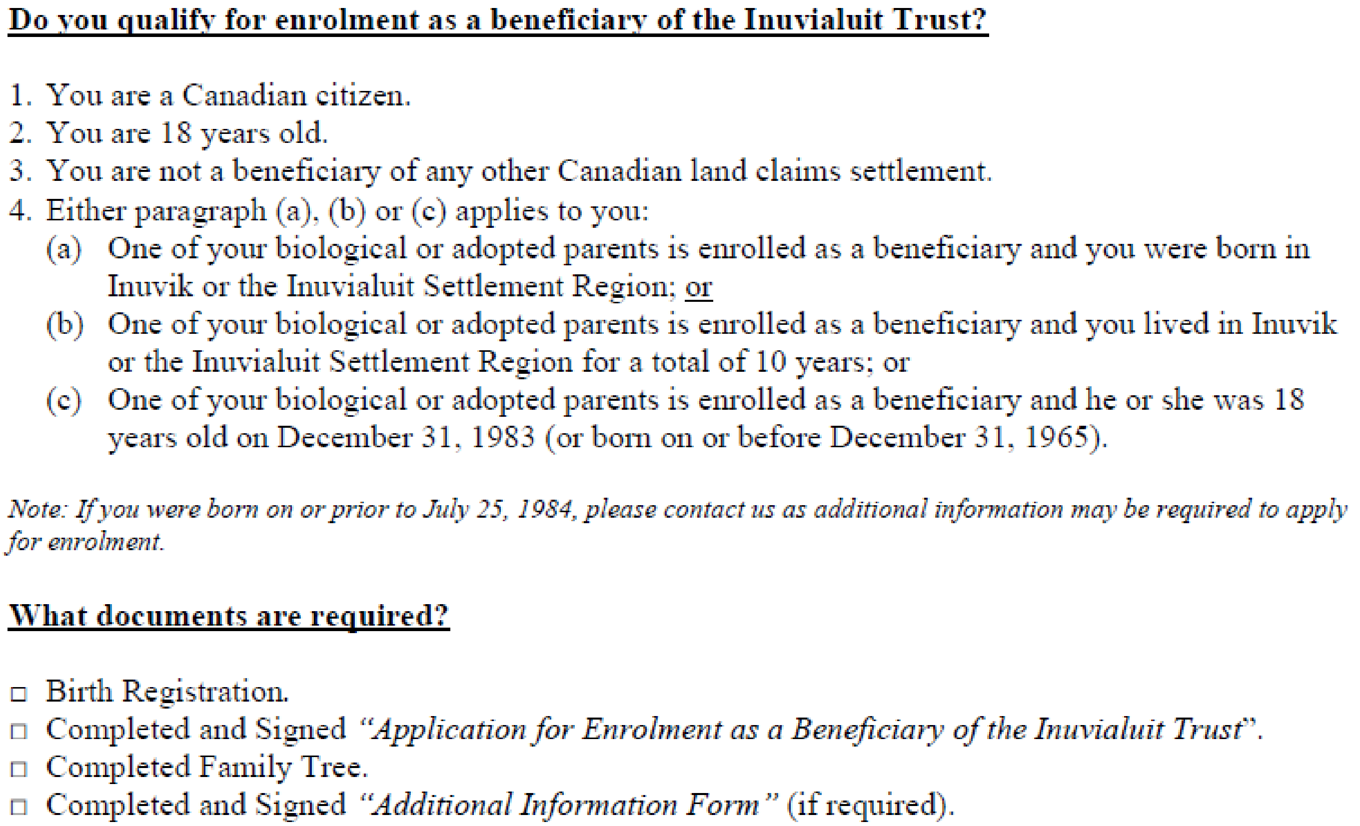
I. DATABASE – Inuvialuit Regional Corporation Enrolment Registry

Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify Select One	
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease	
Users	Primary users of this database - Inuvialuit Regional Corporation and its associated Inuit organizations, relating to IRC's pursuit of its mandate pursuant to the IFA Select One	
Populations	Population groups included in this database – All eligible beneficiaries of the Inuvialuit Trust. Population Coverage - % of population targeted by the database that has been captured: ~ 100% of all eligible beneficiaries of the Inuvialuit Trust. Alternatively, sample with weights? No. If yes, sample size % of population	
Records	Total # of records in database: in 2010, there were 3,904 Inuvialuit beneficiaries. ~ 60% of the beneficiaries live in the ISR or Inuvik; 40% live elsewhere: Aklavik 259 Inuvik 1021 Paulatuk 185 Sachs Harbour 65 Tuktoyaktuk 574 Ulukhaktok 235 Elsewhere 1565	Annual number of records collected/updated: between 2001 and 2009, avg. 123 applicants enrolled each year (between 104 - 135 each year); in 2009, 10 applicants were denied.
Contact/ Questions	Support Organization Inuvialuit Regional Corporation - Inuvialuit Angalatchtyi (Inuvialuit Enrolment Committee) Title of person in support role: Deputy Enrolment Registrar Name: Emily Arey Phone: 867-777-7015 E-mail: earey@irc.inuvialuit.com	
Web site	http://www.irc.inuvialuit.com	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): See key sections of the enrolment application form below:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Do you qualify for enrolment as a beneficiary of the Inuvialuit Trust?

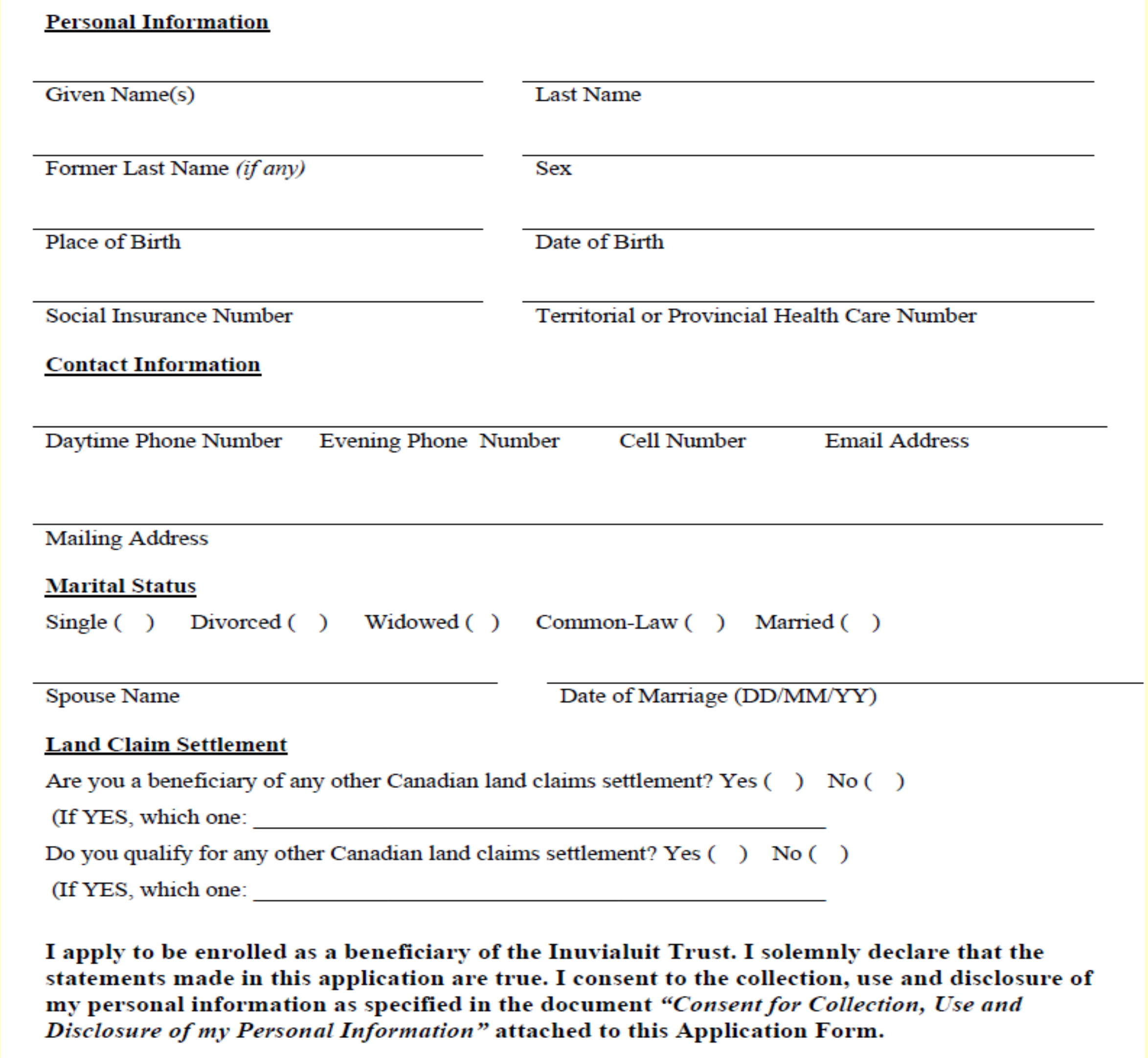
1. You are a Canadian citizen.
2. You are 18 years old.
3. You are not a beneficiary of any other Canadian land claims settlement.
4. Either paragraph (a), (b) or (c) applies to you:
   - (a) One of your biological or adopted parents is enrolled as a beneficiary and you were born in Inuvik or the Inuvialuit Settlement Region; or
   - (b) One of your biological or adopted parents is enrolled as a beneficiary and you lived in Inuvik or the Inuvialuit Settlement Region for a total of 10 years; or
   - (c) One of your biological or adopted parents is enrolled as a beneficiary and he or she was 18 years old on December 31, 1983 (or born on or before December 31, 1965).

Note: If you were born on or prior to July 25, 1984, please contact us as additional information may be required to apply for enrolment.

What documents are required?

- ☐ Birth Registration.
- ☐ Completed and Signed *"Application for Enrolment as a Beneficiary of the Inuvialuit Trust"*.
- ☐ Completed Family Tree.
- ☐ Completed and Signed *"Additional Information Form"* (if required).

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Personal Information

Given Name(s) | Last Name

Former Last Name *(if any)* | Sex

Place of Birth | Date of Birth

Social Insurance Number | Territorial or Provincial Health Care Number

Contact Information

Daytime Phone Number | Evening Phone Number | Cell Number | Email Address

Mailing Address

Marital Status

Single ( ) Divorced ( ) Widowed ( ) Common-Law ( ) Married ( )

Spouse Name | Date of Marriage (DD/MM/YY)

Land Claim Settlement

Are you a beneficiary of any other Canadian land claims settlement? Yes ( ) No ( )

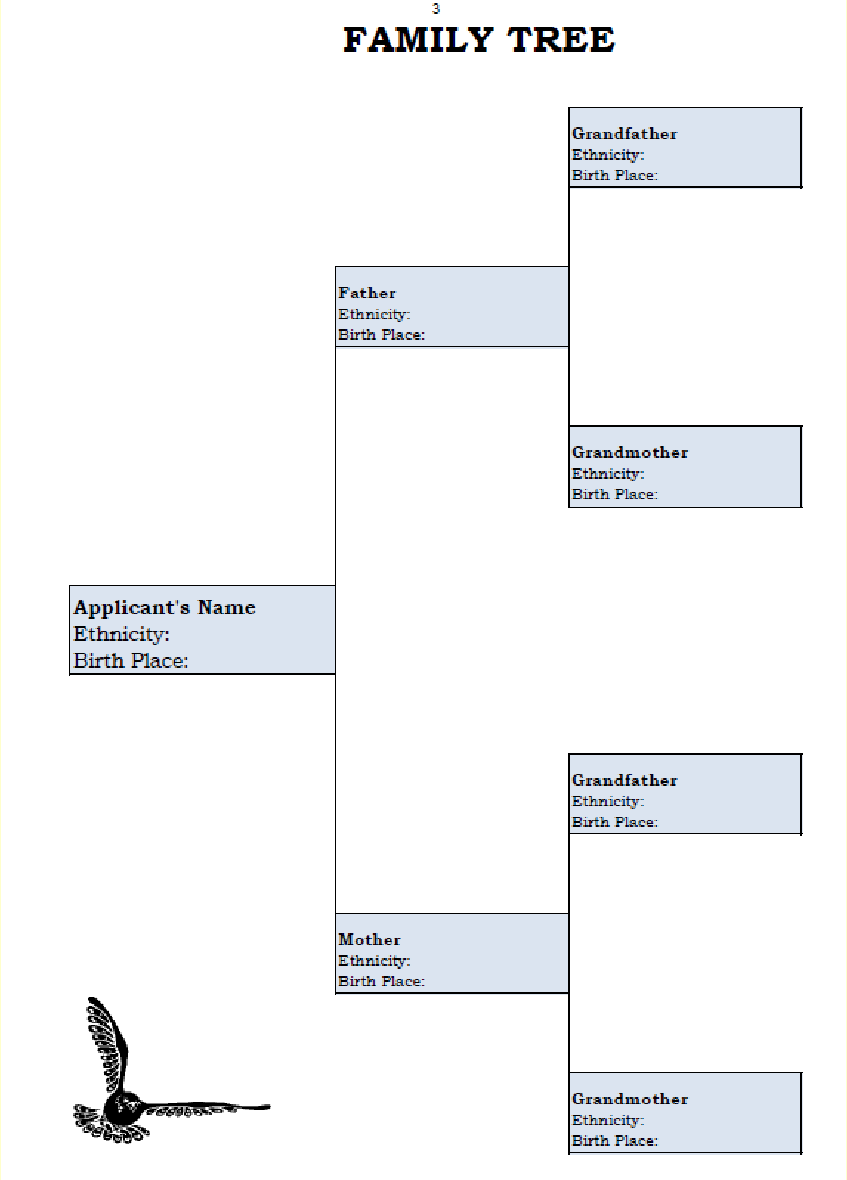
(If YES, which one: ____________________________________

Do you qualify for any other Canadian land claims settlement? Yes ( ) No ( )

(If YES, which one: ____________________________________

I apply to be enrolled as a beneficiary of the Inuvialuit Trust. I solemnly declare that the statements made in this application are true. I consent to the collection, use and disclosure of my personal information as specified in the document *"Consent for Collection, Use and Disclosure of my Personal Information"* attached to this Application Form.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



3

FAMILY TREE

Grandfather
Ethnicity:
Birth Place:

Father
Ethnicity:
Birth Place:

Grandmother
Ethnicity:
Birth Place:

Applicant's Name
Ethnicity:
Birth Place:

Grandfather
Ethnicity:
Birth Place:

Mother
Ethnicity:
Birth Place:

Grandmother
Ethnicity:
Birth Place:

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design	Reason why the above question and/or identifier was chosen: IRC's By-laws #2, which determines the eligibility of persons born after July 25, 1984, was passed in 1985 and has not been amended since. A person has to obtain and complete the "Application Package for Enrolment" and provide a birth registration (see question #11). The "Application Package for Enrolment" can be downloaded from IRC's website (www.irc.inuvialuit.com) or obtained by calling IRC (867-777-2737).	
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report:	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: There are many rights and benefits provided by or derived from the IFA. Beneficiaries benefit from training, employment and business opportunities in the region. Students eligible to enrol can receive financial support from the Inuvialuit Education Foundation (IEF). Elders receive annual payments. Every beneficiary receives a dividend payment annually. This is a non-exhaustive list and you can contact IRC if you need more information on the rights and benefits associated with enrolment. You should notify the Registrar of Enrolment of your child by completing the package "Notification –Child of a Beneficiary" which can be downloaded from the IRC website (www.irc.inuvialuit.com) or obtained by calling IRC (867-777-2737). This is not for the purpose of enrolment since a person can only enrol when he or she turns 18 by submitting an application form (see question #10). However, when you complete and submit the forms and provide a birth registration, a file will be opened for your child. This will allow IRC to confirm if your child will qualify for programs or benefits offered to children by IRC (such as IEF student loans) or by the corporate group (such as the Pivut fare offered by Canadian North). This will also enable IRC to confirm to Health Canada your child's status for the purpose of the Non-Insured Health Benefits Program. The information you provide will also be useful for communication and statistical purposes.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Test /pilot/ evaluation report is available Title/ citation for report:	Select One Select One
Data Linkage	<u>Potential</u>, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Comments on quality (optional)
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:

III. DATA ACCESS

Privacy Constraints

These are stated on the application form: CONSENT FOR COLLECTION, USE AND DISCLOSURE OF MY PERSONAL INFORMATION
In order to fulfill its mandate under the Inuvialuit Final Agreement (IFA), Inuvialuit Regional Corporation (IRC) needs to collect, use and disclose certain personal information about you. The federal legislation protecting your privacy requires that IRC obtain your consent to collect, use and disclose your personal information for identified purposes. We invite you to read this document carefully.

A. PURPOSES. IRC will collect your personal information to determine if you qualify for enrolment, and once you are a beneficiary of the Inuvialuit Trust, for various purposes relating to IRC's pursuit of its mandate pursuant to the IFA which is to represent the Inuvialuit and their rights and benefits.

B. COLLECTION. IRC will collect personal information about you, including:
1. your name, address, phone numbers and other contact information;
2. your date of birth, place of birth, parents, ancestry information, marital information, children, social insurance number, and health care number; and
3. your current and past residences.
IRC may also collect personal information from other sources including federal, territorial, provincial and aboriginal governmental organizations or other third parties.

C. USE AND DISCLOSURE.
1. IRC will use and disclose your personal information for various purposes relating to IRC's pursuit of its mandate pursuant to the IFA.
2. IRC may disclose your personal information to sport, recreation or educational institutions and organizations desirous of confirming the ethnic origins of their participants, members or students.
3. IRC may use and disclose your personal information for statistical, scholarly study or research purposes deemed by IRC to be in the best interest of the Inuvialuit.
4. IRC may disclose your date of birth, place of birth, provincial or territorial health care number and associated community to provincial, territorial or federal health organizations whom require the information to provide you with a non-insured health number.
5. IRC may confirm your and your children's enrolment status and ancestry in connection with child custody and adoption proceedings.
6. IRC may disclose your name and mailing address to Inuvialuit and Inuit organizations such as the Inuvialuit Communication Society and Inuit Tapiriit Kanatami to be used for communication purposes.
7. IRC may disclose your name, associated community, enrolment status, and beneficiary number to the Inuvialuit Community Corporations, Hunters and Trappers Committees, the Gwich'in Tribal Council and other aboriginal organizations for membership list updating and verification purposes.
8. IRC may disclose your name, age, associated community, enrolment status, elder status and beneficiary number to the Inuvialuit Community Corporations to facilitate the administration of benefits, such as IHAP benefits, and the admission to committee, such as an elders' committee.
9. IRC may disclose your name, age and associated community to Canadian North in furtherance of the administration of the Pivut Fare Program.

III. DATA ACCESS

	10. IRC may disclose the enrolment status and social insurance number of a deceased Inuvialuit to funeral service providers. Your personal information collected in one corporate division or branch of IRC may be shared with other divisions of the Inuvialuit Corporate Group for training, employment and business purposes, and for the other purposes identified above.
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Select One Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

4.8.2 Northwest Territories Cancer Registry

I. DATABASE – NWT Cancer Registry				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☒ NT ☐ NV ☐ Other Specify			
Description	Under authority from the NWT Public Health Act and the Disease Surveillance Regulations, the Cancer Registry records all newly diagnosed cases of cancer among NWT residents, who may or may not obtain cancer services outside the territory. Mandatory reporting of cancer in the NWT began in 1990.			
Custodian	The Department of Health and Social Services administers the NWT Cancer Registry.			
	Mandate of Custodian: Promote, protect and provide for the health and well-being of the people of the NWT.			
Purpose	Cancer surveillance - the collection, review and analysis of cancer data so as to describe incidence, prevalence, morbidity, and mortality due to cancer in the population for the purpose of program planning and evaluation.			
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☒ other burden of cancer	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☐ program/service ☒ public policy	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☐ Aboriginal
	☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	The NWT Cancer Registration Form - which is completed for most cancer cases - includes the NWT Health Card Number, including Letter Prefix			
Data Sources	1. NWT Health Care Registration Database: able to Identify ethnic groups by the Health Card Number (HCN). The HCN starts with an alpha character whereby N=Non-Aboriginal, M=Métis, D=Dene, And I=Inuit; 2. Hospital records from Stanton Territorial Hospital and Inuvik Hospital and Alberta Hospitals/Cancer Clinics: Discharge Abstract Database (DAD); 3. Physician database (diagnostic information); 4. Community health database (diagnostic information); 5. Vital Statistics database (mortality records); 6. Pathology reports (Dynacare Kasper diagnostic laboratory); 7. Collaborative Staging (CS) reports from Alberta Cancer Registry (ACR); 8. Canadian Cancer Registry (national record linkage, data sharing, quality assurance)			

I. DATABASE – NWT Cancer Registry

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Before 1990 Month/year of latest available ethno-cultural identifiers: 2011
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Data can be presented according to community type, i.e. 1. Yellowknife, 2. Regional Centres (incl. Hay River, Fort Smith and Inuvik), and "Smaller Communities: (the remaining communities in the NWT). The Registry has access to community-level information.
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Healthcare providers, program planners, researchers. These individuals would not have access to the database. But they would use the information originating from the database. Users external to the Custodian use the database to maintain and manage it. (i.e., Alberta Cancer Board). However they cannot use the information from the database without NWT cancer registrar permission.
	Only users internal to Custodian use the database
Populations	Population groups included in this database – cancer cases diagnosed among permanent residents of the NWT.
Records	Total number of records in database:
Contact/Questions	Support Organization Department of Health and Social Services, Government of the Northwest Territories Title of person in support role: Territorial Epidemiologist, Population Health Name: Maria Santos Phone: Tel 867-920-3241 E-mail: maria_santos@gov.nt.ca
Web site	www.hlthss.gov.nt.ca

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: By linking to two data sets that collect ethno-cultural identifiers at source (the provincial health insurance database and the NWT Vital Statistics database), the NWT cancer registry can assess the burden of cancer among First Nations, Inuit and Métis. The limitation on analysis/ interpretation is not the collection of ethno-cultural data, but the relatively small numbers. To overcome this, data can be aggregated across years, geographic areas, etc. (see comments below).
Data Quality	Since the annual number of cancer cases and deaths in the NWT is relatively small, for statistical purposes, the cancer is aggregated over several years. Age-adjusted rates for each ethnic group or community type can only be compared to the Canadian rate (the reference population), rather than to another ethnic group or community type. E.g. the male Dene age-adjusted rate cannot be compared to the male Inuit rate; it can only be compared to the Canadian male rate. This is due to the method used for age-adjustment.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)

III. DATA ACCESS

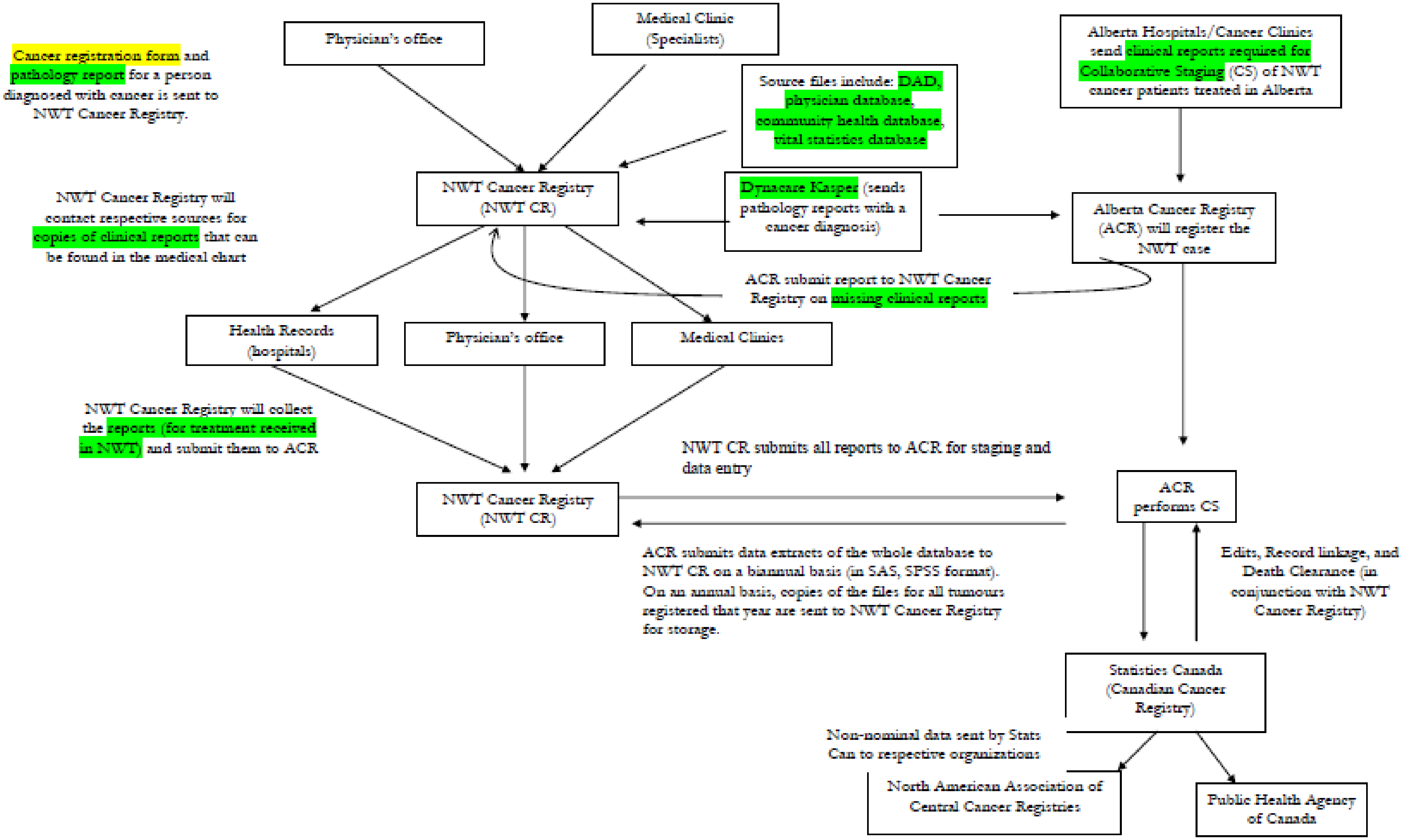
Privacy Constraints	NWT law requires safeguarding data of persons whose cancers are reported to the Registry. In addition, to prevent the identification of individuals with cancer, analyses with five or fewer cases are suppressed. A Privacy Impact Assessment has been done for this database No
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☒ User for decisions Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols No Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Northwest Territories Health and Social Services. (2003). Cancer in the Northwest Territories 1990-2000: A Descriptive Report. 2. Kelly J, Lanier A, Santos M, Healey S, Louchini R, Friborg J, Young K, Ng C. Cancer among the circumpolar Inuit, 1989-2003. I. Background and methods. Int. J Circumpolar Health. 2008;67(5):396-407.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. The report describes the various risk factors for cancer and ways of reducing risk and mortality, e.g. through cancer screening. It concluded that the relatively high number of cancer diagnoses and deaths from colorectal cancer in the territory suggested that a colorectal cancer-screening program warranted consideration and could prove beneficial for NWT residents. 2. The report demonstrated the feasibility and utility of international collaboration in monitoring the changing pattern of cancer in Inuit, a population whose distribution transcends borders. It contributed to the establishment in Yellowknife in 2010 of the Circumpolar Health Observatory (CircHOB), an international collaborative health information system, involved in systematic, standardized, and consistent data collection and analysis. In addition to aggregating online and print resources, CircHOB is population-based, and produces data for all northern regions in all circumpolar countries.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Information requests from Dene Nation have been responded to with information from the registry

IV. DATA USE & REPORTING

Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Below is a graphic description of the data flow that supports the creation of the NWT Cancer Registry, including the ethno-cultural identification of First Nations (Dene), Inuit and Métis people. The Cancer Report was one of the first departmental reports to provide information according to ethnic groups. The next time a similar report is created with ethno-cultural identifiers, it would be prudent to inform and collaborate with the ethnic groups prior.



Cancer registration form and pathology report for a person diagnosed with cancer is sent to NWT Cancer Registry.

Source files include: DAD, physician database, community health database, vital statistics database

Alberta Hospitals/Cancer Clinics send clinical reports required for Collaborative Staging (CS) of NWT cancer patients treated in Alberta

NWT Cancer Registry will contact respective sources for copies of clinical reports that can be found in the medical chart

Dynacare Kasper (sends pathology reports with a cancer diagnosis)

ACR submit report to NWT Cancer Registry on missing clinical reports

NWT Cancer Registry will collect the reports (for treatment received in NWT) and submit them to ACR

NWT CR submits all reports to ACR for staging and data entry

ACR submits data extracts of the whole database to NWT CR on a biannual basis (in SAS, SPSS format). On an annual basis, copies of the files for all tumours registered that year are sent to NWT Cancer Registry for storage.

Edits, Record linkage, and Death Clearance (in conjunction with NWT Cancer Registry)

Non-nominal data sent by Stats Can to respective organizations

4.8.3 Northwest Territories Health Care Plan Client Registry

I. DATABASE – NWT Health Care Plan Client Registry	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☒ NT ☐ NV ☐ Other Specify
Description	Under Canada Health Act guidelines, eligible Northwest Territories (NWT) residents may register for access to medically necessary hospital and physician services. The NWT also provides a supplementary health benefits program specifically for indigenous Métis residents. The Métis Health Benefits (MHB) Program provides additional health benefits similar to Non-Insured Health Benefits, but at a coverage level of 100%. (NIHB is a federally funded program for eligible First Nations people and Inuit, providing coverage for a limited range of health-related goods and services when they are not insured under a Provincial/Territorial health insurance plan.)
Custodian	Northwest Territories - Department of Health and Social Services
	Mandate of Custodian: Promote, protect and provide for the health and well-being of the people of the Northwest Territories.
Purpose	Support the administration of the NWT Hospital Insurance and Health and Social Services Administration Act and the Medical Care Act.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☒ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☒ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☒ Other Indigenous Métis
	☒ Aboriginal ☐ Other Specify
	Each NWT resident enrolled with the NWT Health Care Plan is given a Health Care Card with a personal health number. This number remains the same, regardless of any changes to personal status. Health care administrators and providers are able to identify ethnic groups by the health card number (HCN). The HCN starts with an alpha character whereby N=Non-aboriginal, M=Métis, D=Dene, and T=Inuit.
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: Daily
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Month/year of latest available ethno-cultural identifiers:
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Specify
	Postal Code

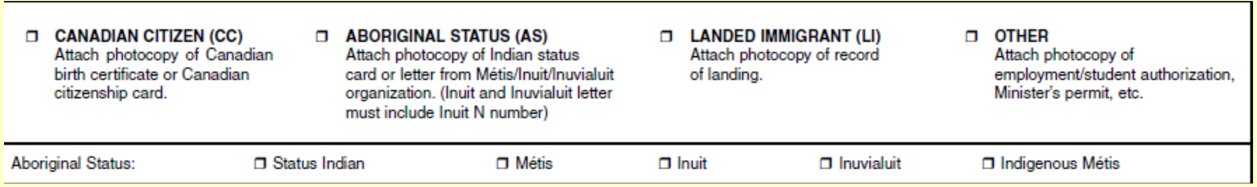
I. DATABASE – NWT Health Care Plan Client Registry

Service Domain	☒ Acute Care ☒ Palliative Care ☒ Cancer ☒ Emergency Care ☒ Long Term Care ☒ Diabetes ☐ Complex Continuing Care ☒ Home & Community Care ☒ Renal Dialysis ☒ Rehabilitation ☒ Primary Care ☒ Immunization ☒ Mental Health/Addictions ☒ Drugs ☒ Communicable Disease
Users	Primary users of this database - Territorial and regional policy makers, health system administrators, and health care providers.
	Database also used by users external to Custodian
Populations	Population groups included in this database – All NWT resident who are eligible for the territorial health insurance plan.
	Population Coverage - % of population targeted by the database that has been captured: The client registry of the NWT Health Care Plan captures ~ 100% of NWT residents eligible for territorial health insurance.
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: Annual number of records collected/updated:
Contact/ Questions	Support Organization Department of Health & Social Services Title of person in support role: Director, Health Services Administration Name: Nick Saturnino Phone: 867-777-7412 E-mail: Nick_Saturnino@gov.nt.ca
Web site	http://www.hlthss.gov.nt.ca/english/health

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s): The health card application process allows NWT residents to voluntarily self-identify at the time of registration - with supporting documentation, as status Indian, Métis, Inuit, Inuvialuit or Indigenous Métis:



☐ **CANADIAN CITIZEN (CC)** Attach photocopy of Canadian birth certificate or Canadian citizenship card.

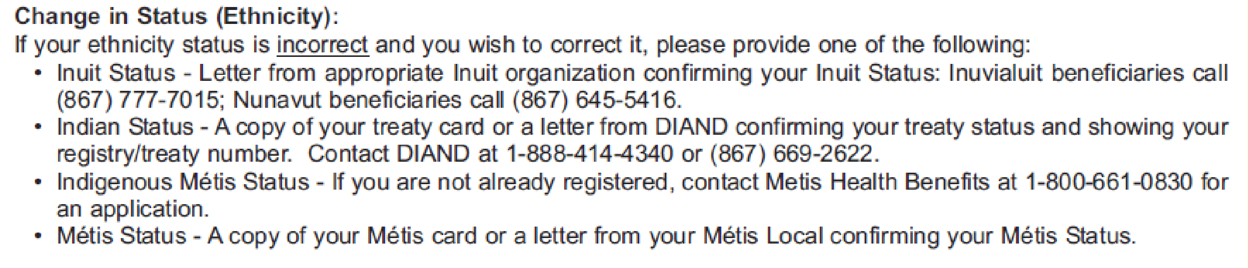
☐ **ABORIGINAL STATUS (AS)** Attach photocopy of Indian status card or letter from Métis/Inuit/Inuvialuit organization. (Inuit and Inuvialuit letter must include Inuit N number)

☐ **LANDED IMMIGRANT (LI)** Attach photocopy of record of landing.

☐ **OTHER** Attach photocopy of employment/student authorization, Minister's permit, etc.

Aboriginal Status: ☐ Status Indian ☐ Métis ☐ Inuit ☐ Inuvialuit ☐ Indigenous Métis

There is also a process to amend the Aboriginal identity registered if a person changes status:

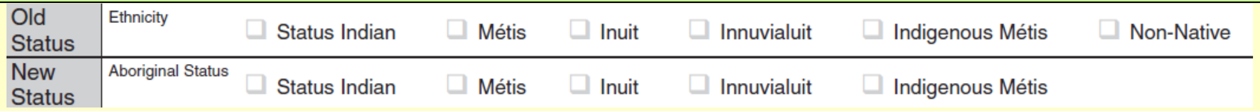


Change in Status (Ethnicity):

If your ethnicity status is incorrect and you wish to correct it, please provide one of the following:

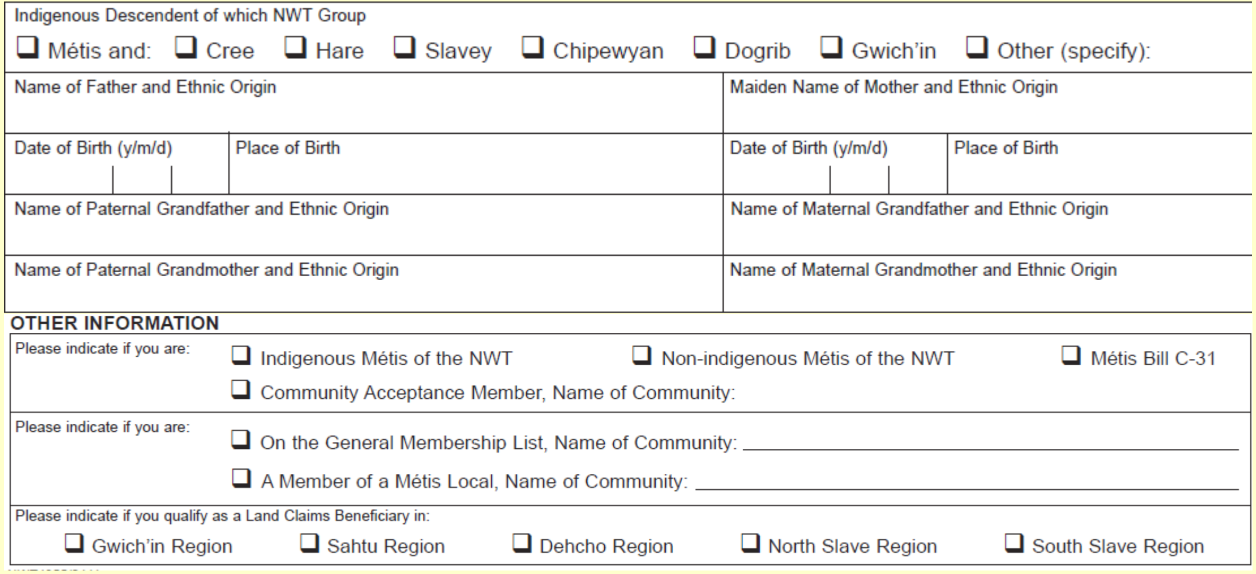
- Inuit Status - Letter from appropriate Inuit organization confirming your Inuit Status: Inuvialuit beneficiaries call (867) 777-7015; Nunavut beneficiaries call (867) 645-5416.
- Indian Status - A copy of your treaty card or a letter from DIAND confirming your treaty status and showing your registry/treaty number. Contact DIAND at 1-888-414-4340 or (867) 669-2622.
- Indigenous Métis Status - If you are not already registered, contact Metis Health Benefits at 1-800-661-0830 for an application.
- Métis Status - A copy of your Métis card or a letter from your Métis Local confirming your Métis Status.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Old Status	Ethnicity	☐ Status Indian	☐ Métis	☐ Inuit	☐ Innuvialuit	☐ Indigenous Métis	☐ Non-Native
New Status	Aboriginal Status	☐ Status Indian	☐ Métis	☐ Inuit	☐ Innuvialuit	☐ Indigenous Métis	

In addition, Métis residents with a valid NWT Health Care Plan number, may also apply for the Métis Health Benefits Program:



Indigenous Descendent of which NWT Group
☐ Métis and: ☐ Cree ☐ Hare ☐ Slavey ☐ Chipewyan ☐ Dogrib ☐ Gwich'in ☐ Other (specify):

Name of Father and Ethnic Origin	Maiden Name of Mother and Ethnic Origin
Date of Birth (y/m/d) | Place of Birth	Date of Birth (y/m/d) | Place of Birth
Name of Paternal Grandfather and Ethnic Origin	Name of Maternal Grandfather and Ethnic Origin
Name of Paternal Grandmother and Ethnic Origin	Name of Maternal Grandmother and Ethnic Origin

OTHER INFORMATION

Please indicate if you are: ☐ Indigenous Métis of the NWT ☐ Non-indigenous Métis of the NWT ☐ Métis Bill C-31
☐ Community Acceptance Member, Name of Community:

Please indicate if you are: ☐ On the General Membership List, Name of Community: ____________________
☐ A Member of a Métis Local, Name of Community: ____________________

Please indicate if you qualify as a Land Claims Beneficiary in:
☐ Gwich'in Region ☐ Sahtu Region ☐ Dehcho Region ☐ North Slave Region ☐ South Slave Region

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen: Within the NWT population of 41,464 (2006 Census), 36.5% are First Nation, 11.1% Inuit (Inuvialuit), and 6.9% Métis, so it is important to be able to ensure that the 50.3% of the population who are Aboriginal receive appropriate services under the territorial and federal health insurance plans.

Ethno-cultural identity question(s) has been tested Select One
Test report re question design is available Select One
Name/citation for test report:

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: In the Northwest Territories, the alpha character on resident's health card is used by a wide variety of health service providers (clinicians and administrators), as well as policy makers and researchers as a starting point to help clients/ patients navigate to the most appropriate services for their needs, as well as monitor population health status and outcomes. Health card numbers are also used within the territory as a key to record linkage across different data sets - within strict parameters for data security, confidentiality and privacy. This ensures that NWT is a jurisdiction that is, and can be, very responsive to the unique needs of First Nations, Inuit and Métis peoples.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated	Select One
	Test /pilot/ evaluation report is available	Select One
	Title/ citation for report:	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest):	Answer 1.
	1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used:	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers	Yes
	Comments on cost (optional): The NWT health insurance client registry is a foundational piece for ethno-cultural identification across many other NWT data sets, e.g. the cancer registry, hospital data sets, etc. While other health care participants are free to augment the health card information with their own data, the availability of the health card ethno-cultural information reduces duplication, with its associated response burden on interviewers and respondents, as well as the time and cost involved.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers	Yes
	Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database	
	A Privacy Impact Assessment has been done for this database	Select One
	Information has been used for secondary purposes	Select One
	If yes, examples of secondary data use:	
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database	Select One
	An MOU or formal agreement governing development and/or use of the database is in place	Select One
	First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as	
	☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions	
	Comments on the nature and/or outcome of engagement (optional):	

III. DATA ACCESS

OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

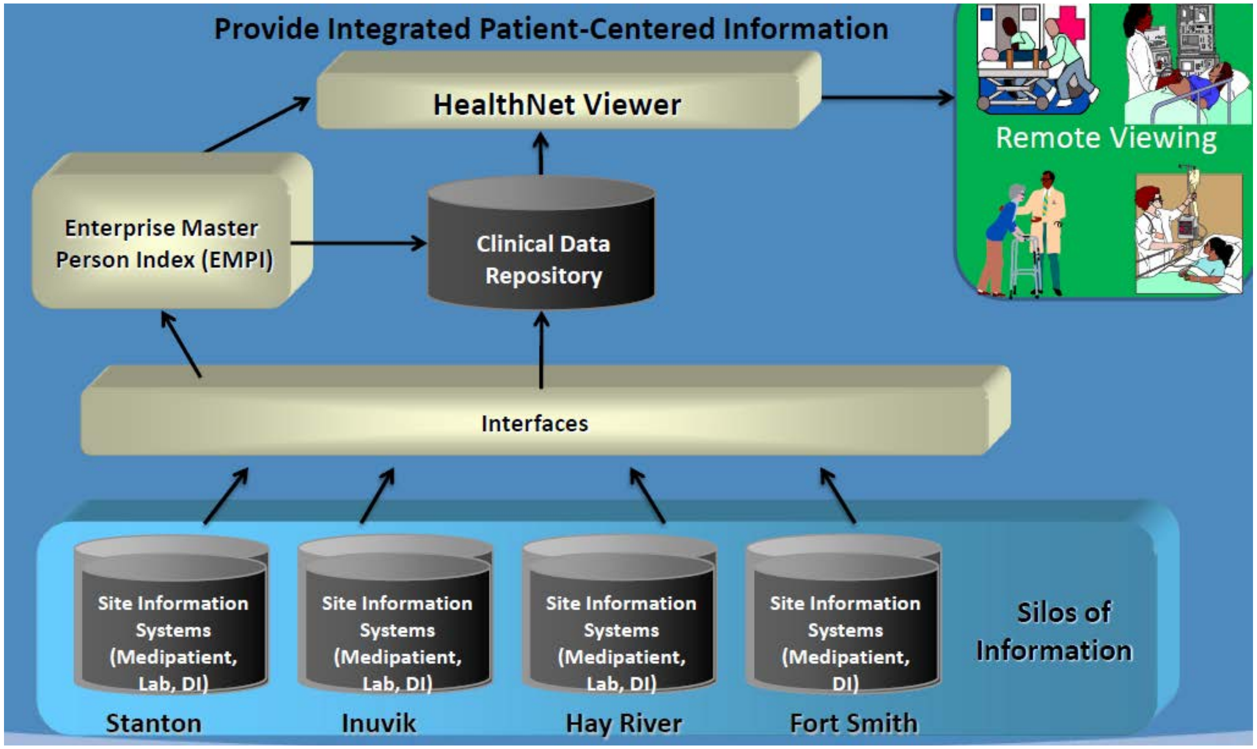
Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Northwest Territories Health Status Report 2010, Government of the Northwest Territories, Health and Social Services, August 2011 2. Physicians Services Report 2008, Government of the Northwest Territories, Health and Social Services, 2008 3. The NWT Health Services Report 2000, Government of the Northwest Territories, Health and Social Services, 2000
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. The identifiers are used to ensure that First Nations, Inuit and Métis groups receive the appropriate territorially and federally funded health benefits they are eligible for; for example, the Government of the NWT facilitates a direct link between its health insurance database and the Status Verification System for the Non-Insured Health Benefits program; 2. Health service providers (clinicians, administrators, public health practitioners, etc.) use the information to monitor health status and outcomes among different ethno-cultural groups, share this with interested stakeholders, identify gaps and collaborate on modifications to programs and services to achieve common health goals in areas ranging from cancer control to maternal/infant health and hospital services.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional):
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment

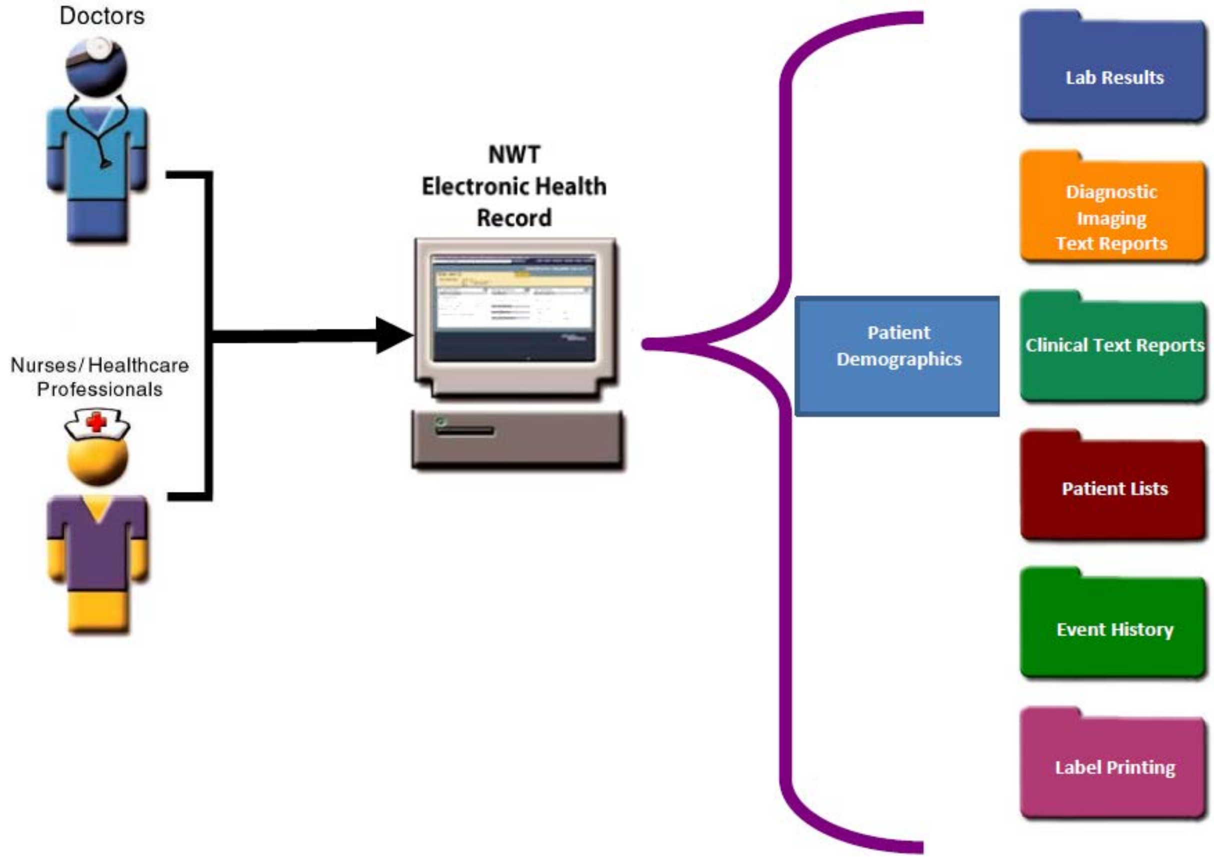
IV. DATA USE & REPORTING

Additional Comments

1. Health reports for NWT can be broken out by demographic variables, including ethnicity and community type, across the different type of services (hospitals, physicians, health centres, public health units and medical travel). Community type can also be a proxy for ethnic differences in the population, as the ethnicity of the population in each type of community varies, with Yellowknife being primarily Non-Aboriginal, the regional centres (Hay River, Inuvik, Fort Smith) about fifty-fifty, and the other communities almost exclusively Aboriginal. In addition, ethno-cultural identifiers can be linked to the territory's cancer, chronic disease surveillance and communicable disease registries. When NWT residents need out-of-territory specialist care (e.g. cancer centres in Alberta), this information is also captured through inter-jurisdictional billing and data exchange.

2. NWT is in the process of rolling out an interoperable electronic health record (iEHR). This iEHR includes an Enterprise Master Person Index, a tool that stores and links demographic and selected personal information (e.g. name, date of birth, medical record number, health card number), and links this to a Clinical Data Repository that is fed by clinical information systems at the frontline. The purpose of the iEHR is to provide clinicians with the information they need to provide patients with most appropriate care (navigation), and to track the care outcomes.
http://www.hlthss.gov.nt.ca/english/services/informatics/interoperable_electronic_health_record.htm




Doctors
Nurses/ Healthcare Professionals
NWT Electronic Health Record
Patient Demographics
Lab Results
Diagnostic Imaging Text Reports
Clinical Text Reports
Patient Lists
Event History
Label Printing

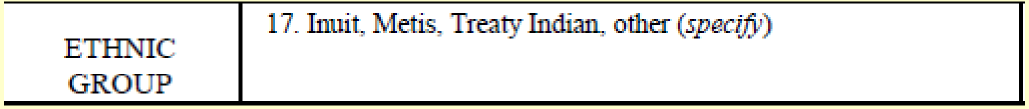
4.8.4 Northwest Territories Vital Statistics Registry

I. DATABASE – NWT Vital Statistics Registry	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☒ NT ☐ NV ☐ Other Specify
Description	The NWT Vital Statistics Act renders compulsory the registration of all live births, stillbirths, marriages, and deaths in the territory.
Custodian	Northwest Territories - Health Services Administration Division, Vital Statistics.
	Mandate of Custodian: To administer and maintain a territory-wide system for registering births, deaths, marriages and stillbirths.
Purpose	Collect demographic information for statistical analysis purposes, as well as facilitate the issuance of birth, marriage and death certificates.
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other
	☐ Aboriginal ☒ Other Can specify another ethnic group.
	Although our Registration of Live Birth form indicates "Inuit" as an option, the clients from Western Arctic are referred to as Inuvialuit.
Status & Update	Database status Active
	Database update frequency Ongoing / on regular frequency Frequency of Updates:
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1920s Month/year of latest available ethno-cultural identifiers:
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease

I. DATABASE – NWT Vital Statistics Registry

Users	Primary users of this database - Vital statistics office, territorial and regional policy makers, health system administrators, and researchers.	
	Database also used by users external to Custodian	
Populations	Population groups included in this database – All people who have been born, married or died in the NWT.	
	Population Coverage - % of population targeted by the database that has been captured:	
	Alternatively, sample with weights? No. If yes, sample size % of population	
Records	Total # of records in database:	Annual number of records collected/updated:
Contact/ Questions	Support Organization Health Services Administration, Vital Statistics	Title of person in support role:
Web site	http://www.hlthss.gov.nt.ca/english/services/vital_statistics	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): The Registration of Live Birth, Death, Marriage and Stillborn process allows NWT residents (fathers and mothers for birth and stillbirth; husband and wife for marriage) to self-identify at the time of registration:  ETHNIC GROUP 17. Inuit, Metis, Treaty Indian, other (*specify*) Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached
Question Design	Reason why the above question and/or identifier was chosen: The above groups represent the main ethnic identity groups in the NWTs.
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report:
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: By linking to other data sets that collect ethno-cultural identifiers at source (e.g. the provincial health insurance database and the NWT cancer registry), the NWT vital statistics registry can assess the burden of disease among First Nations, Inuit and Métis. The limitation on analysis/ interpretation is not the collection of ethno-cultural data, but the relatively small numbers. To overcome this, data can be aggregated across years, geographic areas, etc.
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One Test /pilot/ evaluation report is available Select One Title/ citation for report:
Data Linkage	<u>Potential</u>, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality (optional)	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Select One An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Kelly J, Lanier A, Santos M, Healey S, Louchini R, Friborg J, Young K, Ng C. Cancer among the circumpolar Inuit, 1989-2003. I. Background and methods. Int. J Circumpolar Health. 2008;67(5):396-407. 2. Northwest Territories Health and Social Services. (2003). Cancer in the Northwest Territories 1990-2000: A Descriptive Report.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional):
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional) Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: NWT Vital Statistics has been collecting ethno-cultural data almost from the beginning of records given that fact that it has a predominantly aboriginal population; this will not be as easy to implement in the larger jurisdictions. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers:

4.0 Health Databases – Provincial / Territorial, Regional / Local

4.9 NUNAVUT

4.9.1 Nunavut Cancer Registry

I. DATABASE – Nunavut Cancer Registry				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☒ NU ☐ Other Specify			
Description	The Nunavut Disease Registries Act requires that all cases of cancer diagnosed in a Nunavut resident be reported to the Nunavut Cancer Registry (NCR). Nunavut came into being in 1999, consisting of the Baffin, Kivalliq and Kitikmeot regions of the former Northwest Territories. The NCR retrieved cases whose residence was in what is now within the boundaries of Nunavut from the NWT Cancer Registry retroactively to 1992.			
Custodian	Name of organization that holds database: The custodian is the Territorial Epidemiologist of Nunavut. (NCR is maintained by Cancer Care Ontario on contract to the Nunavut Department of Health and Social Services for the purpose of coding, histology and staging.)			
	Mandate of Custodian: Assess the burden of disease, including cancer, in Nunavut as a basis for continually improving health services.			
Purpose	Principal decision(s) or activities that the information is intended for (in your words): Cancer surveillance - the collection, review and analysis of cancer data so as to describe incidence, prevalence, morbidity, and mortality due to cancer in the population.			
	☒ Public Health & Surveillance	☐ Operating a Health Organization or System	☒ Research	☐ Service Delivery
	☐ screening	☐ funding & reimbursement	☒ population	☐ enrolment/membership
	☐ immunization	☐ transactions, e.g. drug dispensing	☐ clinical	☐ evaluation
	☐ communicable disease	☐ capacity & utilization planning	☐ program/service	☐ equity
	☒ other burden of cancer	☐ performance mgmt. & accountability	☒ public policy	☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☒ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☒ Other Non-registered Métis	☐ Other Specify
	NCR distinguishes Inuit (~85% of the population) and all others in terms of ethnic status. This is done on the basis of the 9-digit code that is assigned to every Nunavut person registered with the Territorial health care insurance plan. The first 8 digits are a unique life-time identifier. The 9th digit is an ethnic identifier, as follows: Dene (3), Métis (4), Inuit (5), Non-Registered Métis (6), Non-Aboriginal (7), Out-of-territory (8).			
Data Sources	1. NU Health Care Plan (source of ethno-cultural identifier); 2. Pathology reports from Baffin Regional Hospital and out-of-province hospitals; 3. Registry report forms from health care professionals; 4. Death certificates from Statistics Canada's Health Statistics Division's Vital Statistics Database; 5. Reciprocal notifications from other Canadian cancer registries.			

I. DATABASE – Nunavut Cancer Registry

	Comments (Optional): Treatment, and often diagnosis of cancer, is generally not undertaken in the territory itself. Most cancer patients are treated in one of 4 out-of-territory cities: Yellowknife, Ottawa, Winnipeg and Edmonton.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1992 Month/year of latest available ethno-cultural identifiers: 2011
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Data can be presented according to region: Baffin, Kivalliq, Kitikmeot.
	Select One
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - A short list of key users: healthcare providers, program planners, researchers
	Database also used by users external to Custodian
Populations	Population groups included in this database – Cancer cases diagnosed among permanent residents of Nunavut.
Records	Total number of records in database: ~ 50 - 70 new tumours are diagnosed in Nunavut each year.
Contact/Questions	Support Organization Government of Nunavut, Department of Health and Social Services Title of person in support role: Territorial Epidemiologist Name: Mike Ruta Phone: 867-975-5917 E-mail: mruta@go.nu.ca
Web site	http://www.gov.nu.ca/health/

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: Provides a consistent, standard method for assessing the burden of disease among different ethnic groups. Of note, incidence/ prevalence numbers in Nunavut can be relatively small, so data often has to be aggregated, e.g. over a number of years. Also, 85% of the Nunavut population is Inuit, so numbers for the other ethnicities are even smaller, making statistically valid comparisons challenging. Nonetheless, the method for assessing and acting on the ethno-cultural data is available.
Data Quality	The Nunavut Cancer Registry is currently going through an audit to validate the data. This is expected to be completed by the end of 2011.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database: Data confidentiality is ensure by strict guidelines for data access which are outlined in Section 12 of the Disease Registries Act. In order to avoid disclosure of any patient's identity, age-specific and site-specific incidence counts are not provided when the total is below 5 cases. A Privacy Impact Assessment has been done for this database No
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Not Applicable An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions Comments on the nature and/or outcome of engagement (optional): Any request for data would go through the Department of Health & Social Services' Research Board, who would consider stipulations in the Nunavut Land Claims Agreement as part of their decision process.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Healy S, Plaza D, Osborne G. A Ten-Year Profile of Cancer in Nunavut, 1992-2001. Iqaluit: Nunavut Department of Health and Social Services; 2003. 2. Kelly J, Lanier A, Santos M, Healey S, Louchini R, Friborg J, Young K, Ng C. Cancer among the circumpolar Inuit, 1989-2003. I. Background and methods. Int. J Circumpolar Health. 2008;67(5):396-407. 3. Upon completion of the database audit currently under way, plans are to conduct an update of the past 10-year trend on the big 3-4 cancers.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)

IV. DATA USE & REPORTING	
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers:

4.9.2 Nunavut Health Care Plan Client Registry

I. DATABASE – Nunavut Health Care Plan - Client Registry	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☒ NU ☐ Other Specify
Description	Under the Canada Health Act, the Government of Nunavut offers the Nunavut Health Care Plan (NHCP). Every person enrolled in the NHCP is given a Health Care Card (HCC) with their own unique nine digit number.
Custodian	Nunavut Health Insurance Programs Office
	Mandate of Custodian: Manage the NHCP, and ensure that enrolled Nunavut residents have access to necessary medical services.
Purpose	Support the administration of the Nunavut Hospital Insurance and Health and Social Services Administration Act and the Medical Care Act. As well, facilitate access - for status Indians and recognized Inuit - to the federal Non-Insured Health Benefits (NIHB) plan, by ensuring they are added to the Status Verification System (SVS).
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☒ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☒ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☒ Other Non-registered Métis
	☐ Aboriginal ☒ Other non-Aboriginal
	The last digit of the Nunavut Health Card number indicates the health benefit entitlement of its holder as follows: 5 = Recognized Inuit, 3 = Status First Nation, 7 = all others except Métis, 4 = Métis, and 6 = Non-registered Métis. Note: there is no Métis health benefits program in Nunavut, nor a Métis organization to administer it; the 4-digit, however, does allow Métis people who provide a Métis registration card, or write in their self-identified status to be recognized as such. A small number of Inuit from Labrador, who fall under the Nunatsiavut land claims agreement, and a small number of Inuit from Inuvialuit are recognized as "all other" (i.e. non-Inuit), as their health benefits are administered under their respective land claims agreements. This means they have to advance health care spending, for which they get reimbursed through their benefit programs.
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: daily
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1999 Month/year of latest available ethno-cultural identifiers: 2011
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other At community level
	Postal Code

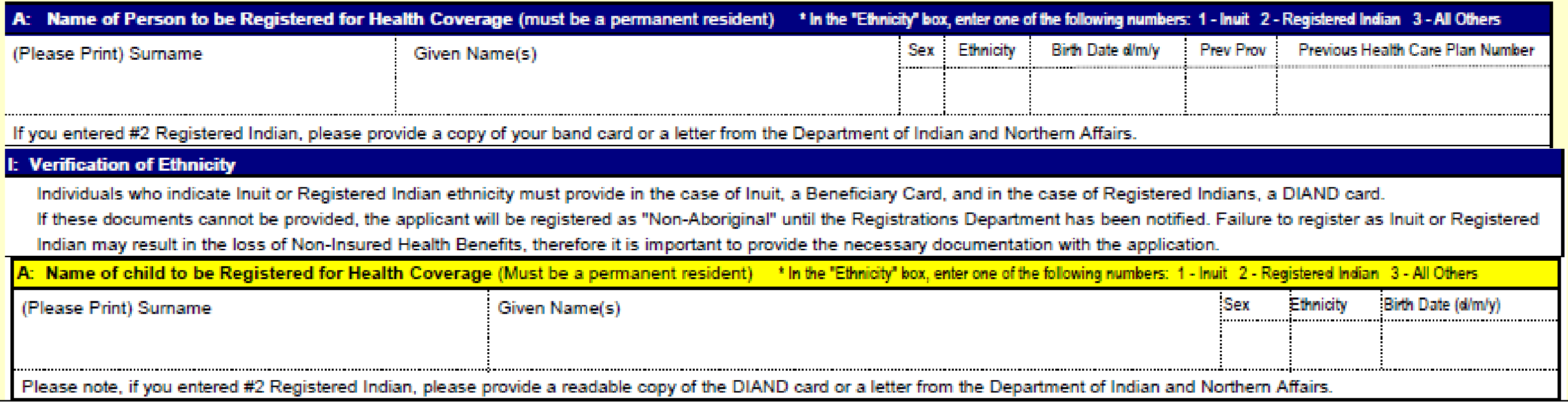
I. DATABASE – Nunavut Health Care Plan - Client Registry

Service Domain	☒ Acute Care ☒ Palliative Care ☒ Cancer ☒ Emergency Care ☒ Long Term Care ☒ Diabetes ☐ Complex Continuing Care ☒ Home & Community Care ☒ Renal Dialysis ☒ Rehabilitation ☒ Primary Care ☒ Immunization ☒ Mental Health/Addictions ☒ Drugs ☒ Communicable Disease
Users	Primary users of this database - Territorial and regional policy makers, health system administrators, and health care providers.
	Database also used by users external to Custodian
Populations	Population groups included in this database – All Nunavut residents who are eligible for the territorial health insurance plan. Note: out-of-territory (OOT) patients are also captured if they require hospital care or need to be medevac'd to nearest facility.
	Population Coverage - % of population targeted by the database that has been captured: The database captures ~ 100% of eligible Nunavut health insurance enrollees.
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: ~ 35,000; ~ 85% of these are Inuit. Annual number of records collected/updated: all records are updated all the time with changes
Contact/ Questions	Support Organization Nunavut Health Insurance Programs Office Title of person in support role: Health Benefits Coordinator Name: Kathleen Irwin Phone: 867-645-8027 E-mail: kirwin@gov.nu.ca
Web site	http://www.hss.gov.nu.ca

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s):



A: Name of Person to be Registered for Health Coverage (must be a permanent resident) * In the "Ethnicity" box, enter one of the following numbers: 1 - Inuit 2 - Registered Indian 3 - All Others

(Please Print) Surname	Given Name(s)	Sex	Ethnicity	Birth Date d/m/y	Prev Prov	Previous Health Care Plan Number

If you entered #2 Registered Indian, please provide a copy of your band card or a letter from the Department of Indian and Northern Affairs.

I: Verification of Ethnicity

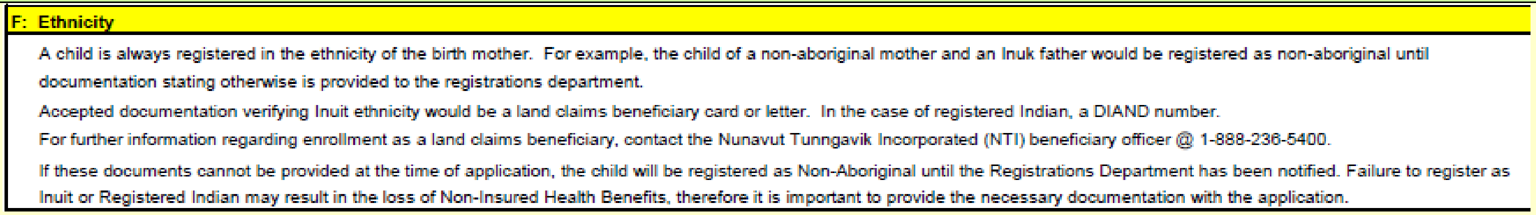
Individuals who indicate Inuit or Registered Indian ethnicity must provide in the case of Inuit, a Beneficiary Card, and in the case of Registered Indians, a DIAND card.
If these documents cannot be provided, the applicant will be registered as "Non-Aboriginal" until the Registrations Department has been notified. Failure to register as Inuit or Registered Indian may result in the loss of Non-Insured Health Benefits, therefore it is important to provide the necessary documentation with the application.

A: Name of child to be Registered for Health Coverage (Must be a permanent resident) * In the "Ethnicity" box, enter one of the following numbers: 1 - Inuit 2 - Registered Indian 3 - All Others

(Please Print) Surname	Given Name(s)	Sex	Ethnicity	Birth Date (d/m/y)

Please note, if you entered #2 Registered Indian, please provide a readable copy of the DIAND card or a letter from the Department of Indian and Northern Affairs.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



F: Ethnicity

A child is always registered in the ethnicity of the birth mother. For example, the child of a non-aboriginal mother and an Inuk father would be registered as non-aboriginal until documentation stating otherwise is provided to the registrations department.

Accepted documentation verifying Inuit ethnicity would be a land claims beneficiary card or letter. In the case of registered Indian, a DIAND number.

For further information regarding enrollment as a land claims beneficiary, contact the Nunavut Tunngavik Incorporated (NTI) beneficiary officer @ 1-888-236-5400.

If these documents cannot be provided at the time of application, the child will be registered as Non-Aboriginal until the Registrations Department has been notified. Failure to register as Inuit or Registered Indian may result in the loss of Non-Insured Health Benefits, therefore it is important to provide the necessary documentation with the application.

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen: Upon signing of the Nunavut Land Claims Agreement, Nunavut Tunngavik Inc. (NTI) took on the Inuit beneficiaries list that up to that time had been managed by the Government of the Northwest Territories. Prior to the establishment of Nunavut, a child was deemed to be Inuit if either its mother and/or its father was Inuit. After the establishment of Nunavut, a child is deemed to be Inuit if its mother is Inuit, but not necessarily if its father is Inuit. In that case, NTI makes the determination following an application process. In addition, NTI broadened the list of Inuit beneficiaries to include Inuit who live outside of the Nunavut Territory.

Ethno-cultural identity question(s) has been tested No
Test report re question design is available No
Name/citation for test report:

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: In Nunavut, the last digit on a resident's health card denotes ethnicity and possible health benefits eligibility, and can be used by a wide variety of health service providers (clinicians and administrators), as well as policy makers and researchers as a starting point to help clients/ patients navigate to the most appropriate services for their needs, as well as monitor population health status and outcomes. Health card numbers are also used within the territory as a key to record linkage across different data sets - within strict parameters for data security, confidentiality and privacy. Examples are the Nunavut Cancer Registry and Nutaqqavut 'Our Children' Health Information System. This ensures that Nunavut is a jurisdiction that is, and can be, very responsive to the unique needs of First Nations, Inuit and Métis peoples.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No
Test /pilot/ evaluation report is available No
Title/ citation for report:

Data Linkage

Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1.

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

Data Quality

Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One

Data quality indicators that are used: Please specify

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done Select One
	Title/citation for test/pilot/quality evaluation report:
	Quality improvement processes include, for example, verifying the (alternate) spelling of names, and requests for back-up documentation (at least two documents) to verify a person's identity. Examples of the latter are: asking for proof of status/registration (e.g. First Nation status card or band card, or Inuit Beneficiary card), driver's license, birth certificate, and in the case of Newborns: the birth mother needs to sign the application. As of the 2006 Census the population of Nunavut was 29,474, with 24,640 people identifying themselves as Inuit (83.6% of the total population), 100 as First Nations (0.34%), 130 Métis (0.44%) and 4,410 as non-aboriginal (14.96%). As of April 1, 2010, Statistics Canada's updated postcensal estimate is 32,887 people in Nunavut.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Comments on cost (optional)
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database: all territorial and federal privacy legislation applies.
	A Privacy Impact Assessment has been done for this database Not Applicable
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: Secondary medical uses, collecting and sharing aggregate statistics
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional): Territorial residents will sometimes show an interest in understanding the rationale behind the ethno-cultural questions.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols No Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Healy S, Plaza D, Osborne G. A Ten-Year Profile of Cancer in Nunavut, 1992-2001. Iqaluit: Nunavut Department of Health and Social Services; 2003. 2. Kelly J, Lanier A, Santos M, Healey S, Louchini R, Friborg J, Young K, Ng C. Cancer among the circumpolar Inuit, 1989-2003. I. Background and methods. Int. J Circumpolar Health. 2008;67(5):396-407.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional):
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Nunavut's approach was modeled on the approach in the Northwest Territories.
	Thoughts/advice on factors that would <u>Support</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Nunavut and the Northwest Territories are the only jurisdictions in Canada that do seamless, behind-the-scenes work to facilitate their eligible territorial health insurance plan enrollees getting onto the Status Verification System, so these enrollees receive Non-Insured Health Benefits. In southern provinces, this process is managed through FNIHB regional offices. But potential beneficiaries, or adopted children in southern Canada, may not know that, and hence lose benefits they are entitled to. <u>Limit</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	The Government of Nunavut has launched Phase I of its plan to create a territory-wide electronic health record that will link all 26 of its facilities that deliver patient care. The Nunavut health care model is fully integrated, with all care managed by the Department of Health & Social Services (DHSS). This includes public health, home care, primary care, out-patient clinics, mental health and acute care. As of February 2011, patient demographic information, such as chart number, age and sex for the majority of the 32,000 residents had been entered in the EHR, and existing pharmacy, laboratory and patient registration systems were replaced. Phase II (late 2011) will see the implementation of clinical documentation.

4.9.3 Nunavut Inuit Enrolment List

I. DATABASE – Nunavut Inuit Enrolment List				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☒ NU ☐ Other Specify			
Description	Nunavut Tunngavik Incorporated (NTI) is responsible for enrolling individuals as Beneficiaries of the Nunavut Land Claims Agreement (NLCA). A person who is on the Inuit Enrolment List is entitled to benefit from the NLCA so long as he or she is alive. Inuit agreed to make NTI the Designated Inuit Organization. Enrolment is guided by the principle that Inuit are best able to define who is an Inuk for the purpose of benefiting from the NLCA.			
Custodian	The process is administered by NTI through the Enrolment Division of the Department of Human Resources, and the Community Enrolment Committees.			
	Mandate of Custodian: Article 35 of the NLCA requires a Designated Inuit Organization to ensure that all eligible Inuit of the Nunavut Settlement Area have the opportunity to be enrolled. Nunavut Tunngavik Incorporated (NTI) represents the Inuit of Nunavut, the beneficiaries with respect to the lands and resources they now hold under the Nunavut Land Claims Agreement. It is responsible for the management of the funds received under the settlement on behalf of the Inuit and, along with regional Inuit organizations, for safeguarding Inuit interests regarding implementation of the Agreement.			
Purpose	A person who is on the Inuit Enrolment List is entitled to benefit from the NLCA so long as he or she is alive.			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☐ First Nation/North American Indian	☐ Inuit/Inuk	☐ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☒ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	The geographic scope of the enrolment process includes the entire Nunavut Settlement Area, and includes Inuit from that area residing elsewhere. The NLCA (Sub-section 35.3.1 (b)) states that a person must be a Canadian citizen to qualify for enrolment. A person who is not a Canadian citizen is not eligible. The NLCA (Sub-section 35.3.1 (c)) states that a person must be an Inuk according to Inuit customs and usages. This criterion is consistent with the recognition contained in the NLCA (Sub-section 35.1.1(a)) that Inuit are best able to define who is an Inuk. The NLCA (Sub-section 35.3.1 (d)) states that a person must identify himself or herself as an Inuk. A person who does not identify as an Inuk is not eligible. All enrolled Nunavut Inuit are entitled to receive a Nunavut Inuit Enrolment Card, providing evidence of their status as a Nunavut Inuk under the NLCA.			
Status & Update	Database status Active In order to ensure that it is kept current in an efficient manner, the Enrolment List shall be maintained in the form of a computerized database, with copies maintained as appropriate for the purposes of security.	Database update frequency Ongoing / on regular frequency Frequency of Updates: It shall be the responsibility of a person enrolled as a Nunavut Inuk to inform the NTI Enrolment Division of the Department of Human Resources of any change of name, or of any error in the spelling of his or her name on the Enrolment List or an Enrolment Card. Informing the NTI Enrolment Division may be done by completing and submitting to NTI an Enrolment Change and Correction Form.		

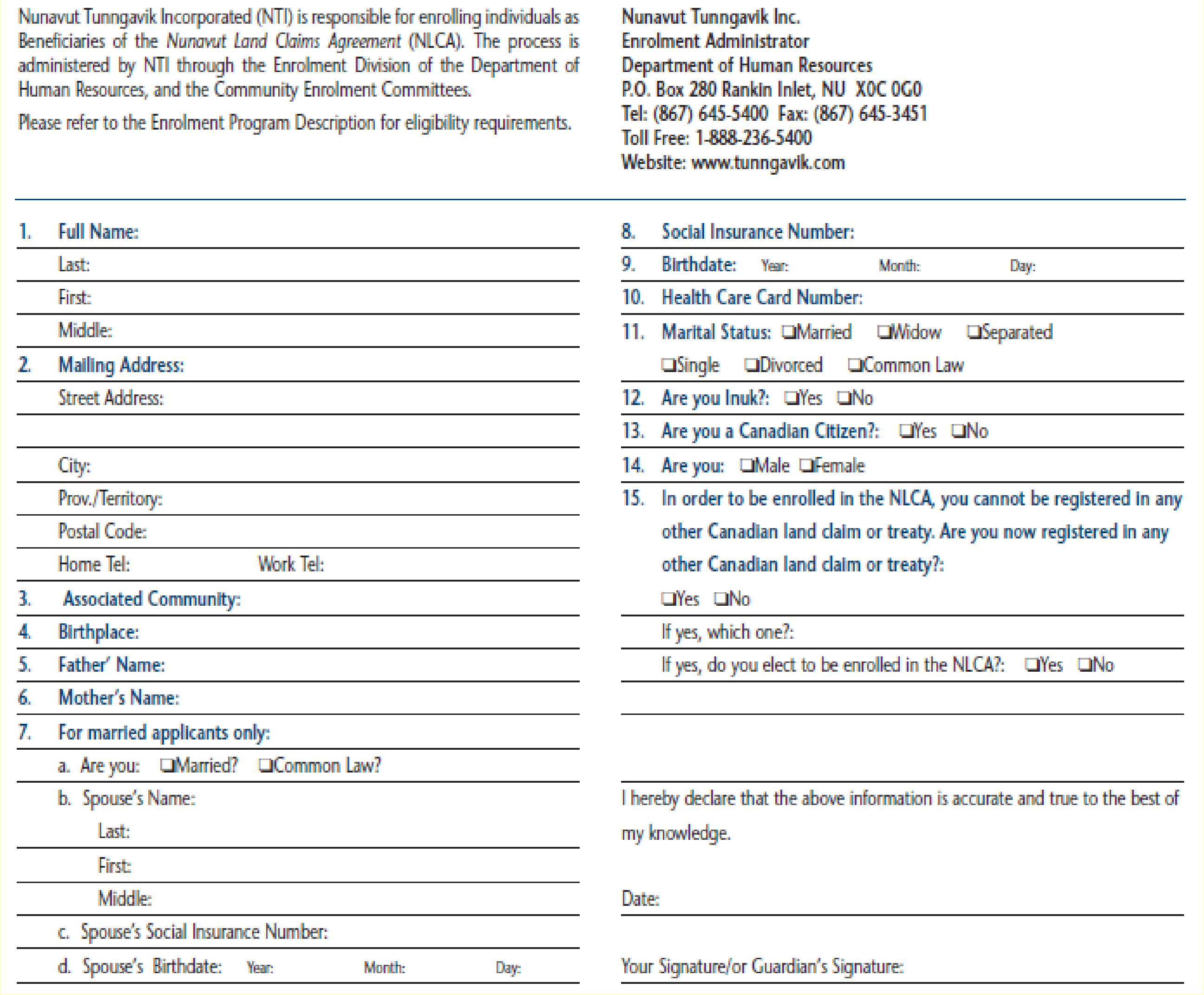
I. DATABASE – Nunavut Inuit Enrolment List

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1993	Month/year of latest available ethno-cultural identifiers: 2011
Level of Detail	1. Select One 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One	
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify	
	Postal Code	
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease	
Users	Primary users of this database - Nunavut Tunngavik Incorporated and its associated Inuit organizations: Nunavut Trust, Regional Inuit Associations, Inuit Regional Development Corporations, etc. Cf. NTI Organizational Chart on http://www.tunngavik.com/about/. (NTI) ensures that promises made under the Nunavut Land Claims Agreement (NLCA) are carried out. Inuit exchanged Aboriginal title to all their traditional land in the Nunavut Settlement Area for the rights and benefits set out in the NLCA. The management of land, water and wildlife is very important to Inuit. NTI coordinates and manages Inuit responsibilities set out in the NLCA and ensures that the federal and territorial governments fulfill their obligations.	
	Select One	
Populations	Population groups included in this database – all eligible Inuit of the Nunavut Settlement Area.	
	Population Coverage - % of population targeted by the database that has been captured: ~ 100% of eligible Inuit of the Nunavut Settlement Area	
	Alternatively, sample with weights? No. If yes, sample size % of population	
Records	Total # of records in database: Today, there are approximately 23,000 Inuit beneficiaries in the Nunavut Settlement Area (NSA); Inuit constitute approximately 85 percent of the population of the NSA. From: ANNUAL REPORT FOR 2004-2006 . The Implementation of the Nunavut Land Claims Agreement . FINAL TEXT VERSION.	Annual number of records collected/updated:
Contact/ Questions	Support Organization Nunavut Tunngavik Inc. Title of person in support role: Enrolment Administrator Name: Margaret Kusugak Phone: 867-645-5400 E-mail: MKusugak@tunngavik.ca	
Web site	www.tunngavik.com	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Are you Inuk? Yes No (see enrolment application form below):

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Nunavut Tunngavik Incorporated (NTI) is responsible for enrolling individuals as Beneficiaries of the *Nunavut Land Claims Agreement* (NLCA). The process is administered by NTI through the Enrolment Division of the Department of Human Resources, and the Community Enrolment Committees.

Please refer to the Enrolment Program Description for eligibility requirements.

Nunavut Tunngavik Inc.
Enrolment Administrator
Department of Human Resources
P.O. Box 280 Rankin Inlet, NU X0C 0G0
Tel: (867) 645-5400 Fax: (867) 645-3451
Toll Free: 1-888-236-5400
Website: www.tunngavik.com

1. **Full Name:**
   Last:
   First:
   Middle:
2. **Mailing Address:**
   Street Address:
   City:
   Prov./Territory:
   Postal Code:
   Home Tel: Work Tel:
3. **Associated Community:**
4. **Birthplace:**
5. **Father' Name:**
6. **Mother's Name:**
7. **For married applicants only:**
   a. Are you: ☐Married? ☐Common Law?
   b. Spouse's Name:
      Last:
      First:
      Middle:
   c. Spouse's Social Insurance Number:
   d. Spouse's Birthdate: Year: Month: Day:
8. **Social Insurance Number:**
9. **Birthdate:** Year: Month: Day:
10. **Health Care Card Number:**
11. **Marital Status:** ☐Married ☐Widow ☐Separated ☐Single ☐Divorced ☐Common Law
12. **Are you Inuk?:** ☐Yes ☐No
13. **Are you a Canadian Citizen?:** ☐Yes ☐No
14. **Are you:** ☐Male ☐Female
15. **In order to be enrolled in the NLCA, you cannot be registered in any other Canadian land claim or treaty. Are you now registered in any other Canadian land claim or treaty?:**
    ☐Yes ☐No
    If yes, which one?:
    If yes, do you elect to be enrolled in the NLCA?: ☐Yes ☐No

I hereby declare that the above information is accurate and true to the best of my knowledge.

Date:

Your Signature/or Guardian's Signature:

Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached

Question Reason why the above question and/or identifier was chosen: The Nunavut Land Claims Agreement (NLCA), also referred to as the Nunavut Final Agreement:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Design

- Was signed on May 25, 1993 in Iqaluit by representatives of the Tunngavik Federation of Nunavut (TFN), the Government of Canada (GC), and the Government of the Northwest Territories (GNWT);
- Was ratified by Inuit and the federal government according to the ratification provisions of the Agreement, and came into force on July 9, 1993; and
- Involves the largest number of beneficiaries and the largest geographic area of any land claim agreement in Canadian history.

Ethno-cultural identity question(s) has been tested No
Test report re question design is available No
Name/citation for test report:

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Allows for Inuit-specific information in support of NTI priorities. See also "Additional Comments".

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No
Test /pilot/ evaluation report is available No
Title/ citation for report:

Data Linkage

Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Select One

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

Data Quality

Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
Data quality indicators that are used: Please specify	
Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
Title/citation for test/pilot/quality evaluation report:	
Comments on quality (optional)	

Data Cost

This approach replaces a more costly way to collect ethno-cultural identifiers Select One
Comments on cost (optional)

Capacity

The custodian plans to keep collecting the ethno-cultural identifiers Yes
Barriers - if any – to ongoing collection of ethno-cultural identifiers:

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Select One An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Select One Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Good, Inuit-specific information that can substantiate the positions of Nunavut Tunngavik Incorporated and advocate for funds is a priority for the organization. The Inuit Health Survey, for example, was an important project that resulted in Inuit-specific community data, and also demonstrated the growing capabilities of NTI in the area of research. As part of the Inuit Health Survey, which had Adult and Child Questionnaires, community members helped to identify Inuit participants for both survey participation, and for coming on the ship to participate in clinical assessments. Over the past 5 years, it has been a priority to collect more Inuit-specific community data and build research capacity. The Beneficiaries list is an important resource for this.

4.9.4 Nutaqqavut ‘Our Children’ Health Information System

I. DATABASE – Nutaqqavut 'Our Children' Health Information System	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☒ NU ☐ Other Specify
Description	Nutaqqavut 'Our Children' Health Information System (NHIS) is a standardized way to document health information about pregnant women, new mothers and young children throughout Nunavut.
Custodian	Chief Medical Officer of Health, Government of Nunavut
	Mandate of Custodian: To promote, protect and enhance the health and well-being of all Nunavummiut, incorporating Inuit Qaujimajatuqangit at all levels of service delivery and design.
Purpose	Nunavut is the most northerly jurisdiction in Canada of which 85% of inhabitants are Inuit. Although most infants are born healthy, Nunavut leads the country for adverse early child health outcomes such as infant mortality, rates of birth defects, prematurity and low birth weight. Public health and community efforts are needed to understand and improve outcomes.
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☒ other maternal/ child
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☐ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☐ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☐ equity ☒ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
Data Sources	The data for the Nutaqqavut Health Information System is already being collected by health care providers. The Nutaqqavut Health Information System simply collects all this information in one database. Data collection begins at the first prenatal visit and continues through to preschool. It compiles data from a number of existing sources: 1. Nunavut Prenatal Records 1, 2, 3 - identifies mother and father as Inuk, Dene, Other First Nation, Métis, or Non-Aboriginal (see end of Profile) 2. Nunavut Labour & Delivery Records 1, 2 3. Nunavut Newborn Record 4. Hospital Discharge Summary 5. Well Child Forms: 2, 6 & 12mths, 2-3yrs & 4-5yrs 6. Birth Defect Reporting Form - identifies infant as Inuk, Dene, First Nation, Métis, Other, or Unknown (see end of Profile)

I. DATABASE – Nutaqqavut 'Our Children' Health Information System

	7. Nunavut Health Care Plan - The last digit of the Nunavut Health Card number indicates the health benefit entitlement of its holder as follows: 5 = Recognized Inuit, 3 = Status First Nation, 7 = all others except Métis, 4 = Métis.
	The full extent of the adverse birth outcomes, birth defects and other chronic diseases of childhood in Nunavut need appropriate exploration and action. Current data sources, such as those collected for the Canadian Institute for Health Information are not ideal as they are largely limited to analysing in-patient hospital discharge summaries and death certificates, which can skew the results of small populations if data contains inaccuracies. Databases which include direct source reporting are known to be more informative. Although health surveys provide cross-sectional views that are helpful to provide background and to institute change, ongoing assessments of determinants and outcomes relevant to the population need to be planned carefully. The relatively low absolute number - albeit high rate - of births in Nunavut (about 800/year) but the greater risk of adverse birth outcomes justifies the development of a comprehensive reporting system to understand and improve outcomes. Modelled after current provincial systems that collect prenatal, perinatal and birth defect information, a comprehensive system responding to local maternal–child health needs will provide the tools for further research and intervention to improve outcomes. A system that considers the issues as a continuum from 16 weeks gestation until pre-school was therefore explored and decided upon.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Database system will be ready by Fall 2011 for data input Month/year of latest available ethno-cultural identifiers:
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☒ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☒ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - The aggregate information would be available to communities, health care providers and others interested in promoting maternal–child health; all uses of the database by users external to the Custodian require the proper approval and permissions. Database also used by users external to Custodian
Populations	Population groups included in this database – Nunavut infants and their mothers
Records	Total number of records in database: Expected ~ 800 newborns/ year
Contact/ Questions	Support Organization Government of Nunavut, Department of Health and Social Services Title of person in support role: Project Manager Name: Misty Malott Phone: +1 (867) 975-5727 E-mail: NHIS@gov.nu.ca
Web site	http://www.hss.gov.nu.ca/en/Your%20Health%20NSS.aspx

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE	
Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: A diverse group of professional and lay stakeholders were brought together initially to determine local interest including NTI (Nunavut Tunngavik Incorporated) the organization responsible for the land and the people of Nunavut. Following this, a series of small working groups were held to decide on potential prenatal, perinatal and early child health variables, to be documented. Over 100 Nunavut participants have now had some role in the development of the system which has been initiated. Pre-existing standard prenatal forms and well-child assessment forms have been modified to include "Nunavut specific" variables of nutrition, food and domestic security, exposures in pregnancy, birth defects, development, chronic diseases of childhood and paternal information including ethno-cultural identifiers.
Data Quality	The NHIS Data Coordinator will be responsible for ensuring the quality of data entered into the NHIS. This individual will review information for completeness and accuracy and rectify each and every instance of incompleteness and/or inaccuracy by either contacting the appropriate NHIS participant, by chart review, or by accessing patient information via iEHR to ensure the highest standards of data quality. The Data Coordinator will also develop and maintain a list of common problems with specific regard to the collection forms. This information will be reviewed on an annual basis and will be used to update the collection forms and/or plan educational sessions to reduce further instances of collection error and increase data quality.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes New Labour & Delivery, Prenatal, Well-Child and Birth Defect Reporting forms have been created for use with the NHIS. These forms were in the process of significant updating as the NHIS project was beginning. The NHIS fields have been incorporated into the new forms to reduce extra paper work on the part of nurses, midwives and physicians. Although some forms may initially take longer to complete, as HCPs become more familiar with the forms, the time to complete the forms should diminish. Ultimately, effective use of the information gathered through the NHIS will allow better health planning and programming, with the goal of enhanced health and decreased demand on HCPs. Database development: Existing database systems nationally and internationally were assessed. Cost efficiency, technology support and ease of adaptation were all considered. It was decided that Nunavut's database would be an integration of 3 sub-database systems, adopting 2 that were already well-established and had been in existence for at least 20 years: the B.C. Perinatal Database Registry (39) and EUROCAT (40), a European multi-jurisdictional birth defect database. The third subdatabase would be a custom-made, overarching system incorporating the 2 existing databases and the Nunavut-specific fields at every time interval from 16 weeks gestation until birth, 2 months, 6 months, 1 year, 2–3 years and preschool.

III. DATA ACCESS

Privacy Constraints

The revised prenatal records and well-child assessments will be kept in the hospital and community health charts of the mothers and children, simply replacing previous records. The information will be considered confidential as is all patient chart information. Individual identifiers will be removed upon transfer of copies to the data centre, which houses epidemiology information for Health and Social Services Nunavut, but a unique identifier will allow accurate longitudinal collection of information. The information as entered in the database will be used only for population health assessments. From the database, no individual access will be possible, preventing any individual release to third parties. A new Public Health Act for Nunavut is currently being developed and will take into consideration the need for collection of health information to improve the health status of residents but also protect patient privacy and confidentiality. In the interim, in June 2011, permission was obtained from the Nunavut Cabinet to collect health information for the purposes of the Nutaqqavut (Our Children) Health Information System (NHIS).

- Privacy will be protected in several ways:
- Only the data entry clerk for the NHIS will view individual data and only for the purposes of entering it into the database. This access will be subject to strict confidentiality/privacy protections.
- Each patient will be given a unique code and information will not be associated with individual identity.
- Information will be made public in aggregate form only (such as yearly rates of prematurity).
- Information from small communities will be pooled when needed to further protect privacy.
- Individual privacy is protected by law under Nunavut legislation.
- This database should not be confused with e-medical records which provide individual information to HCPs involved in care.

Since the purpose of the collection of data for NHIS is to improve the health of the population under the public health strategy, and not to be used for individual care Cabinet approved the collection and consolidation of health data for the purposes of the NHIS on June 30, 2011.

A PIA will be done with partial funding and expertise support from the Public Health Agency of Canada (PHAC).

A Privacy Impact Assessment has been done for this database Yes

First Nations, Inuit, and/or Métis Engagement

First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes
An MOU or formal agreement governing development and/or use of the database is in place No
First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as

☐ Designer (e.g. of question)	☒ Collector of data	☐ Custodian	☒ Analyst	☒ User for decisions

This comprehensive maternal–child health information system has been developed with the extensive involvement of Nunavut Tunngavik Incorporated, along with the input of health care providers and other stakeholders. NTI are considered partners, and support the system to improve child health. They have a representative on the executive advisory committee.

OCAP

The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:

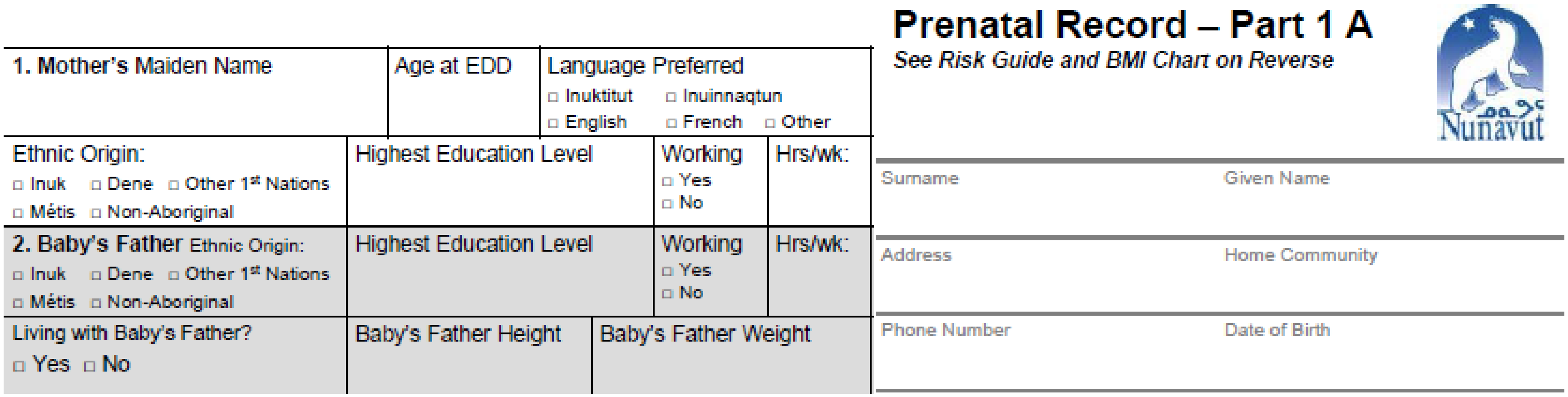
First Nations OCAP principles Select One	Inuit Land Claims research protocols Yes	Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: 1. Just being implemented, no data has been analyzed to date. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. NA 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes The development of the Nunavut Health (Our Children) Information System initiative takes into consideration the unique issues of this northern jurisdiction, developing a system relevant to its population's needs through broad collaboration. The goal is to understand and prevent adverse outcomes and to include information on favorable outcomes that will enhance understanding. The information system offers the opportunity to develop baseline statistics and to observe changes longitudinally with interventions and time. The involvement of various levels of the community ensured local relevance in that the initiative would take into consideration the opinions of front-line health care providers and other stakeholders such as NTI. It is hoped that this information system model will be useful for other similar populations. A communication strategy is underway. Territory-wide teleconferences have been held and brochures have been developed, for both the public and health care providers. Posters will be placed in health centres.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would <u>Support</u> the re-application of this ethno-cultural identification approach to other jurisdictions: 1) the project is based on a real health gap: Nunavut leads the country for adverse early child health outcomes such as infant mortality rates, birth defects, prematurity and low birth weight. This is the starting point for broad support from public health medical officers, local clinicians, nurses, midwives and community health representatives, as well as lay Inuit stakeholders; 2) the project has been > 6 years in the making - building broad based support inside and outside the Territory for collaborative action. This has resulted in funding over time from the Department of Health & Social Services (Government of Nunavut), including Canada Prenatal Nutrition Program (CPNP), Public Health Agency of Canada (PHAC) and Canadian Institutes of Health Research (CIHR). As well, it has resulted in broad based participation and input into the development of the forms, database and supporting implementation tools that are necessary for success; 3) the project has adopted standards validated elsewhere (Canada and international - leveraging established best practices, and allowing for cross-jurisdictional comparisons) where it can, yet has been sensitive to adapt to local information needs where necessary; 4) the project team has planned for communication, privacy provisions, governance and research input through a research advisory board. for further information, cf. The development of a comprehensive maternal–child health information system for Nunavut-Nutaqqavut (Our Children). Samantha Lauson, Sarah McIntosh, Natan Obed, Gwen Healey , Sirisha Asuri , Geraldine Osborne, Laura Arbour. Int J Circumpolar Health 2011; 70(4):363-372.

IV. DATA USE & REPORTING

	Limit the re-application of this ethno-cultural identification approach to other jurisdictions: The potential of using the entire Health Information System may be different for different jurisdictions. For example, in B.C. (45,000 births/ year) and Ontario (>100,000 births/ year) such a comprehensive system would likely not be possible; however, both these provinces do very well with focused perinatal outcomes and birth defect surveillance. The specifics of NHIS are uniquely possible and justified based on the health issues of priority and the low absolute number of births per year. The specifics of multi-stakeholder collaboration will change with the different contexts of different jurisdictions too. However, some broad principles - as outlined above - will likely still apply: 1) a real, well-described need, 2) taking time for building relationships, which in turn yield participation and resources, 3) adopting validated standards where possible, customizing where necessary, 4) a comprehensive approach, which includes communication, privacy, governance and research planning.
Additional Comments	Collecting data with NHIS will give health professionals the ability to: ☐ Assess maternal and child health ☐ Identify causes and risk factors for various health conditions ☐ Develop prevention strategies, programs and services ☐ Evaluate maternal and child health initiatives ☐ Illustrate territorial trends ☐ Compare Nunavut to other jurisdictions in Canada and in the circumpolar region ☐ Identify the way maternal health, early pregnancy and childhood influences impact adult health and development of chronic disease



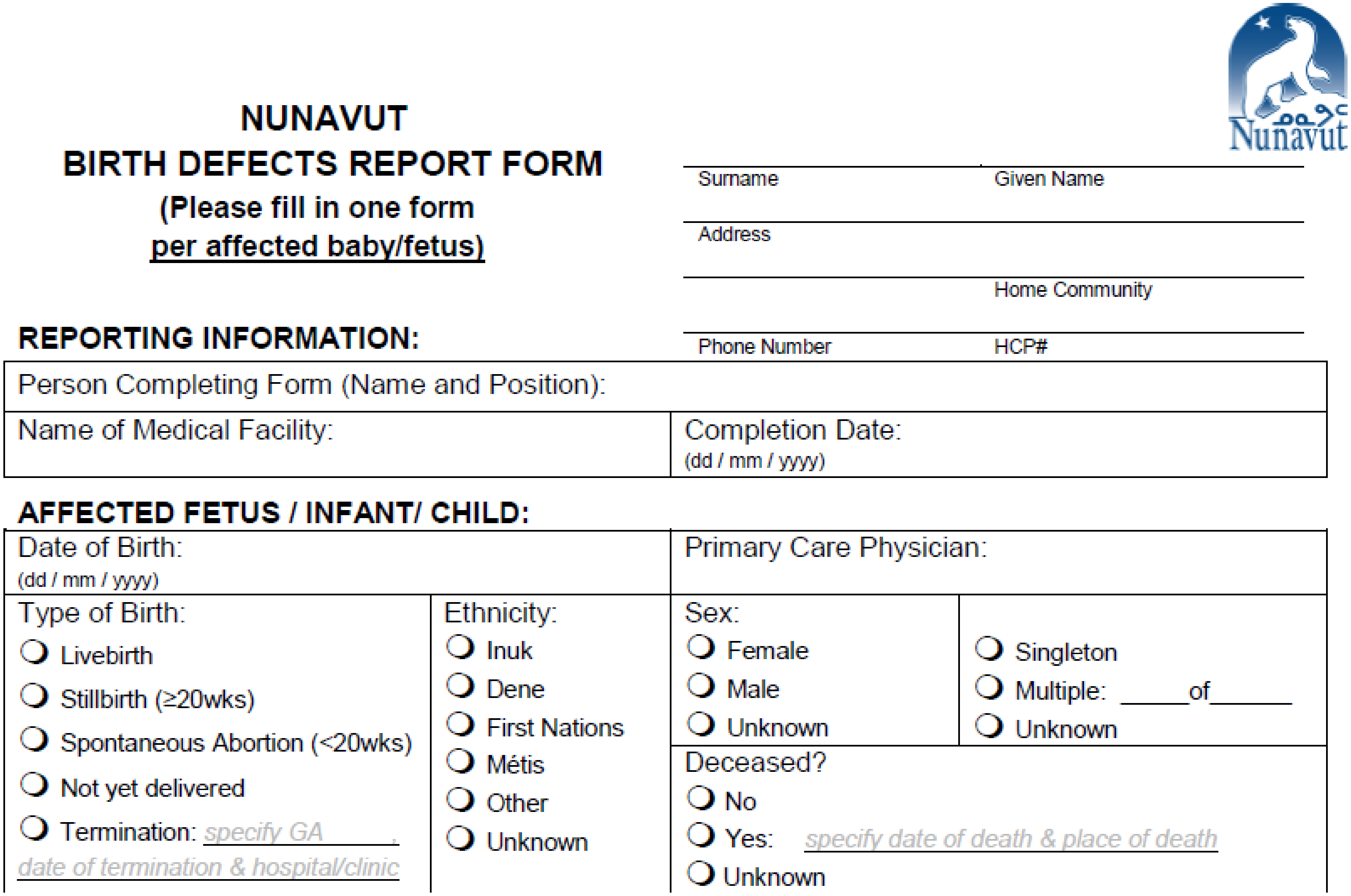
Prenatal Record – Part 1 A

See Risk Guide and BMI Chart on Reverse

Nunavut

1. Mother's Maiden Name	Age at EDD	Language Preferred ☐ Inuktitut ☐ Inuinnaqtun ☐ English ☐ French ☐ Other	
Ethnic Origin: ☐ Inuk ☐ Dene ☐ Other 1st Nations ☐ Métis ☐ Non-Aboriginal	Highest Education Level	Working ☐ Yes ☐ No	Hrs/wk:
2. Baby's Father Ethnic Origin: ☐ Inuk ☐ Dene ☐ Other 1st Nations ☐ Métis ☐ Non-Aboriginal	Highest Education Level	Working ☐ Yes ☐ No	Hrs/wk:
Living with Baby's Father? ☐ Yes ☐ No	Baby's Father Height	Baby's Father Weight	

Surname	Given Name
Address	Home Community
Phone Number	Date of Birth



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Nunavut

NUNAVUT
BIRTH DEFECTS REPORT FORM

(Please fill in one form
per affected baby/fetus)

Surname
Given Name
Address
Home Community
Phone Number
HCP#

REPORTING INFORMATION:

Person Completing Form (Name and Position):	
Name of Medical Facility:	Completion Date: (dd / mm / yyyy)

AFFECTED FETUS / INFANT/ CHILD:

Date of Birth: (dd / mm / yyyy)		Primary Care Physician:	
Type of Birth: ○ Livebirth ○ Stillbirth (≥20wks) ○ Spontaneous Abortion (<20wks) ○ Not yet delivered ○ Termination: *specify GA , date of termination & hospital/clinic*	Ethnicity: ○ Inuk ○ Dene ○ First Nations ○ Métis ○ Other ○ Unknown	Sex: ○ Female ○ Male ○ Unknown	○ Singleton ○ Multiple: _____of______ ○ Unknown
		Deceased? ○ No ○ Yes: *specify date of death & place of death* ○ Unknown	

5.0 Health Databases – National

5.1 NATIONAL FIRST NATIONS,INUIT AND MÉTIS DATABASES

5.1.1 First Nations Regional Health Survey (RHS)

I. DATABASE – First Nations Regional Health Survey (RHS)				
Geography	☒ Canada ☒ BC ☒ AB ☒ SK ☒ MB ☒ ON ☒ QC ☒ NB ☒ NS ☒ PE ☒ NL ☒ YT ☒ NT ☐ NU ☐ Other Specify			
Description	The First Nations Regional Health Survey (RHS) is the only First Nations governed, national health survey in Canada. It is longitudinal in nature and collects information for and with the First Nation on-reserve and northern First Nations communities population based on both Western and traditional understandings of health and wellbeing. Information covers > 30 topic areas including demographics, language, housing, health status, culture, and community development.			
Custodian	First Nations Information Governance Centre (FNIGC). The RHS National Team is located at the First Nations Information Governance Centre in Ottawa and coordinates the RHS on a national level. Activities include preparing reports, serving as the data steward, and engaging in partnerships. In addition, ten independent, RHS Regional Partners coordinate the RHS in their respective regions. The National Team and Regional Partners collaborate on collective issues as well as share ideas and knowledge. The RHS National Team is mandated and authorized to report on national level statistics; it cannot provide or report on regional level statistics. Each Region is completely independent and responsible for its own respective databases and reporting.			
	Mandate of Custodian: The Assembly of First Nations (AFN) Chiefs in Assembly, the Chiefs Committee on Health (CCOH) and First Nations Regions across the country have mandated FNIGC to provide oversight and governance over the RHS. FNIGC membership is derived from the RHS regional organizations, and thus, provides a solid regional and community based foundation for governance.			
Purpose	To collect, analyze and apply cross sectional, comparable data over time that reflects First Nations conceptualization of health. The process is controlled by First Nations, based on the priorities of First Nations communities, and respects the First Nations principles of OCAP. The Regional Health Survey (RHS) is the foremost national First Nations survey that has produced important innovations in data sharing, research ethics, computer-assisted interviewing, sampling, field methods and training, and culturally appropriate questionnaire content. Most significantly, the RHS process has invested in individual and institutional First Nations capacity at the community, regional and national levels. The RHS is a unique collaborative initiative of First Nations regional organizations across Canada.			
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☒ other healthy behaviours	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☐ program/service ☒ public policy	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☐ Inuit/Inuk	☐ Métis	☐ Aboriginal
	☒ Status (registered, treaty) ☐ Non-status ☒ On-reserve ☐ Off-reserve ☒ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	Comments (Optional)			
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates: every 4 years		
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1997	Month/year of latest available ethno-cultural identifiers: 2008-2010		

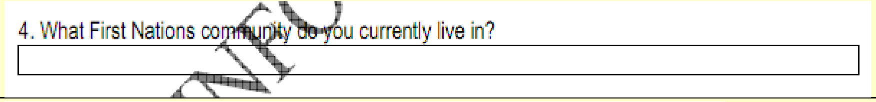
I. DATABASE – First Nations Regional Health Survey (RHS)

Level of Detail	1. Individual Record 2. If Individual Record was selected: Select One 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☒ National ☒ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Band level Municipality
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☒ Palliative Care ☐ Long Term Care ☒ Home & Community Care ☒ Primary Care ☐ Drugs ☒ Cancer ☒ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Federal/ provincial governments, national, regional and local First Nations entities, their health committees and the First Nations communities and leadership. Only users internal to Custodian use the database
Populations	Population groups included in this database – The RHS Phase 2 (2008) is composed of three main survey components: 1) Adult (age 18 years and over, self-reported); 2) Youth (age 12-17 years, self-reported); 3) Child (age 0-11 years, completed by primary care giver). A unique aspect of RHS is the Community Survey, which deals with factors at a broader community level and is filled out with local community expert(s). Population Coverage - % of population targeted by the database that has been captured: 5.3% Alternatively, sample with weights? Yes. If yes, sample size Adult, Youth and Children Surveys conducted in 216 First Nations Communities with 72.5% of the target sample achieved and 21,757 surveys collected.
Records	Total # of records in database: The RHS Phase 2 was initiated in 2008 and completed in the fall of 2010. The target sample for Phase 2 was 30,000 First Nation individuals in 250 First Nations communities in the 10 participating regions across Canada. The sampling approach for this Phase has been improved (from that of Phase 1). In RHS Phase 2, 72.5% of the target was achieved and in total, 21,757 surveys were collected in 216 First Nations communities. Annual number of records collected/updated:
Contact/ Questions	Support Organization First Nations Information Governance Centre Title of person in support role: RHS National Project Manager Name: Jane Gray Phone: 613-733-1916 ext. 102 E-mail: jgray@fnigc.ca
Web site	www.fnigc.ca

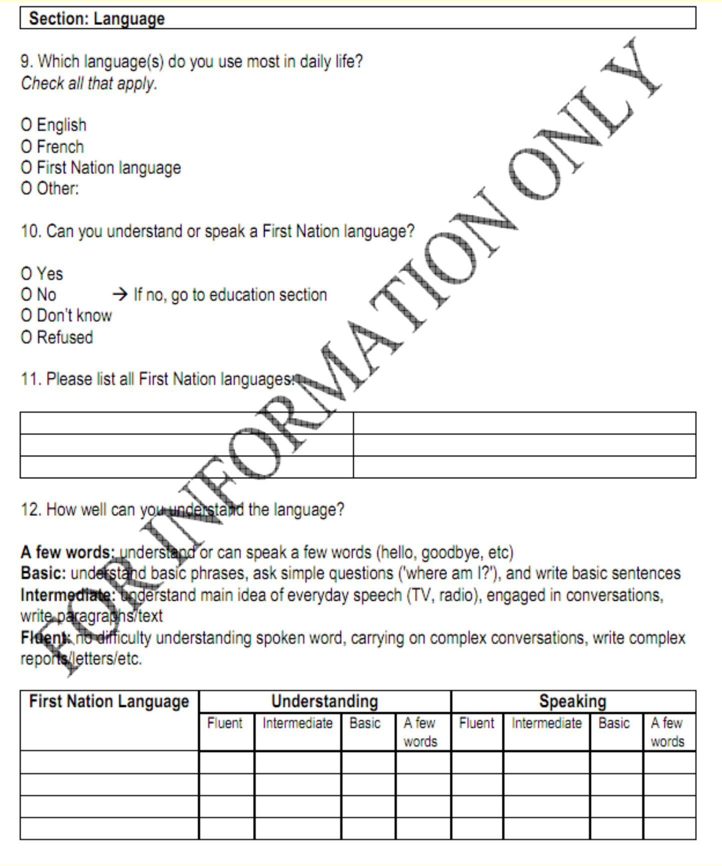
II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s): The survey is administered on First Nations on reserve and in northern First Nations communities , and uses community membership lists to identify respondents. In addition, the following survey questions provide more ethno-cultural identity details:



4. What First Nations community do you currently live in?



Section: Language

9. Which language(s) do you use most in daily life?
Check all that apply.

○ English
○ French
○ First Nation language
○ Other:

10. Can you understand or speak a First Nation language?

○ Yes
○ No → If no, go to education section
○ Don't know
○ Refused

11. Please list all First Nation languages:

12. How well can you understand the language?

A few words: understand or can speak a few words (hello, goodbye, etc)
Basic: understand basic phrases, ask simple questions ('where am I?'), and write basic sentences
Intermediate: understand main idea of everyday speech (TV, radio), engaged in conversations, write paragraphs/text
Fluent: no difficulty understanding spoken word, carrying on complex conversations, write complex reports/letters/etc.

First Nation Language	Understanding				Speaking			
	Fluent	Intermediate	Basic	A few words	Fluent	Intermediate	Basic	A few words

FOR INFORMATION ONLY

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design	Reason why the above question and/or identifier was chosen: Please describe	
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report:	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: 1) RHS fills a gap left by large national population based surveys which exclude sampling from reserves. 2) Many provincial/ national population based surveys do not provide respondents an opportunity to self-identify their (Aboriginal) ethno-cultural affiliation, 3) the RHS is about self-determination in the area of research and it is First Nations themselves that will govern how its information is collected and used by outsiders. It means governance over ‘information” and governance over “information management”. RHS collects quality data from First Nation communities and it is First Nation leadership that will use this information to showcase the realities of First Nation communities based on sound quality data and lobby for policy changes. RHS provides the data for First Nations leadership to bring about change for First Nations communities. 4) Besides comprehensive community engagement, RHS is about capacity building for First Nations people and communities through their active involvement in the design, administration, analysis and use of the survey.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One Test /pilot/ evaluation report is available Select One Title/ citation for report:	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Select One 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	An independent review was completed by Harvard University’s Project on American Indian Economic Development in 2006. The Harvard Review Team found that the RHS Phase 1 (2002/03) iteration of the survey was technically rigorous, included numerous improvements over the RHS 1997 pilot survey and had many advantages relative to other surveys internationally. “Compared to … surveys of Indigenous people from around the world, … RHS was unique in First Nations ownership of the research process, its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people … at each stage of the research process.” The Review assessed the following: I. Sampling design: identification and selection of target population, sampling scheme, achieved sample size, respondent selection, and response rate; II. Data collection: informed consent, mode of collection, questionnaire design, and data quality; III. Data analysis and dissemination: data analysis plan, data cleaning, coding and documentation, data analysis training, data presentation, data	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	dissemination and interpretation; IV. In addition, each of the above three areas were assessed in terms of their congruence with the principles of OCAP. Source: REVIEW OF THE FIRST NATIONS REGIONAL LONGITUDINAL HEALTH SURVEY (RHS) 2002/2003, 2006 Harvard Project on American Indian Economic Development
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:

III. DATA ACCESS

Privacy Constraints	RHS is guided by strict privacy protocols as well as a Code of Ethics and these protocols will be maintained at the FNIGC. Individual and community privacy are the core principles that drive the RHS and FNIGC. The RHS is the first national survey implemented explicitly in keeping with the First Nations principles of OCAP - Ownership, Control, Access and Possession. As the only national research initiative under complete First Nations control, the RHS has given new meaning to First Nations self-determination in research and provided the research community with a demonstration on how the principles of OCAP can be successfully executed. A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: yes - CIHR funded secondary analysis
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Yes First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) | ☒ Collector of data | ☒ Custodian | ☒ Analyst | ☒ User for decisions Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Yes | Inuit Land Claims research protocols Not Applicable | Métis requirements Not Applicable

IV. DATA USE & REPORTING	
Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. RHS Phase 2 (2008/10) Preliminary Results for Adult, Youth, Child, Revised Second Edition June 2011; 2. First Nations Regional Longitudinal Health Survey (RHS) 2002/03, Results for Adults, Youth and Children Living in First Nations Communities, November 2005; 3. First Nations Regional Longitudinal Health Survey (RHS) 2002/03, The Peoples' Report, Revised Second Edition March 2007; for links to these and other RHS-related reports, including Regional Reports, please see http://www.fnigc.ca/node/6
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Conference presentation and disseminations of product to First Nations communities in Canada, international indigenous presentations
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional) Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

5.1.2 Inuit Health in Transition Study

<table>
<tr><th colspan="5">I. DATABASE – Inuit Health in Transition Survey</th></tr>
<tr><td>Geography</td><td colspan="4">☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☒ QC ☐ NB ☐ NS ☐ PE ☒ NL ☐ YT ☒ NT ☒ NU ☐ Other Specify</td></tr>
<tr><td>Description</td><td colspan="4">The Inuit Health in Transition Study (IHTS), also referred to as the Inuit Health Survey, refers to a collection of international health surveys of Inuit residing in arctic regions. Internationally, surveys were conducted in Norton Sound (Alaska) and West Greenland. In Canada, the study included Inuit residing in Nunavik, Nunavut, the Northwest Territories and Labrador. Remote communities were visited by an icebreaker ship, where participating community members were transported by barge or helicopter to participate in an interview and survey, undergo paraclinical examination and provide biological samples. Members of the ship survey team included interviewers, nurses, laboratory technicians and specialists. While the initial survey was cross-sectional, investigators aim to repeat the study in future to be able to track changes in the health of this population over time.
Qanuippitaa? is the name of the 2004 Nunavik Health Survey, which was part of the IHTS. For the purposes of this profile, the health survey conducted in 2007/2008 in the Inuvialuit Settlement Region, Nunavut and Nunatsiavut, entitled “Qanuqitpit? Qanuippitali? Kanuivit?” (How about us? How are we?) will be described. Steering committees in the Inuvialuit Settlement Region, Nunavut and Nunatsiavut created partnerships between educational institutes, representatives of Inuit communities and organizations involved in developing and conducting the Inuit Health Survey. Qanuippitali? is a collaboration between the Centre for Indigenous Peoples' Nutrition and Environment at McGill University, the Inuvialuit Regional Corporation, the Nunatsiavut government, the Government of Nunavut and Nunavut Tunngavik Incorporated, among others.</td></tr>
<tr><td>Custodian</td><td colspan="4">The Centre for Indigenous Peoples' Nutrition and Environment (CINE) at McGill is the custodian and administrator, and site of physical storage.</td></tr>
<tr><td></td><td colspan="4">Mandate of Custodian: The guiding principles of CINE are to:
• Document, promote and incorporate traditional knowledge of nutrition and environment
• Respond to concerns of local communities on their food, food use and environment
• Develop participatory relationships between communities and scientists for undertaking research in nutrition and ecosystems
• Encourage continuing consultation, communication and recognition of elders to enhance the relevance of CINE's work
• Implement ethics guidelines for research, including those related to intellectual property rights as adopted by University Councils and the CINE Board
• Provide training to students and other residents of local communities
• Communicate research findings widely, both nationally and internationally, and contribute to policy developments in areas related to the CINE mission</td></tr>
<tr><td>Purpose</td><td colspan="4">It is the purpose of the project to study the effects on health and disease of the lifestyle transition that takes place among the Inuit, with special emphasis on changing diet and reduced physical activity.</td></tr>
<tr><td></td><td>☒ Public Health & Surveillance
☐ screening
☐ immunization
☐ communicable disease
☐ other Specify</td><td>☐ Operating a Health Organization or System
☐ funding & reimbursement
☐ transactions, e.g. drug dispensing
☐ capacity & utilization planning
☐ performance mgmt. & accountability</td><td>☒ Research
☒ population
☒ clinical
☐ program/service
☒ public policy</td><td>☐ Service Delivery
☐ enrolment/membership
☐ evaluation
☐ equity
☐ patient navigation</td></tr>
</table>

I. DATABASE – Inuit Health in Transition Survey

Demographics	☒ Database includes demographic data ☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers ☐ First Nation/North American Indian: ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number ☒ Inuit/Inuk: ☒ Inuvialuit ☒ Nunavut ☐ Nunavik ☒ Nunatsiavut ☐ Métis: ☐ On Métis register ☐ Other ☐ Aboriginal: ☐ Other Inuit from Nunavik were included in another, complementary sub-study entitled Qanuippitaa? (2004).
Status & Update	Database status Inactive Database update frequency Ongoing / on regular frequency Frequency of Updates: Aim to repeat in 2015
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 2007 Month/year of latest available ethno-cultural identifiers: 2008
Level of Detail	1. Individual Record 2. If Individual Record was selected: Not identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Select One
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☒ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☒ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - The database is only accessible to the administrator of the database and data entry staff who have two-tier security clearance. Only users internal to Custodian use the database
Populations	Population groups included in this database – Participants came from 24 coastal communities in Nunavut, 4 in the Inuvialuit Settlement Region and 5 in Nunatsiavut. Households in each community were randomly selected to participate in the Inuit Health Survey. An adult survey was administered to men and women aged 18 and older and a child survey was offered for children aged three to five. Participants in the “Qanuqitpit? Qanuippitali? Kanuivit?” study belong to an international cohort designed to have comparable health data for 12,000 arctic residents. Population Coverage - % of population targeted by the database that has been captured: Approximately 12% of people from each community were randomly selected to participate. Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: 2,100 Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Inuit Health Survey Steering Committee Title of person in support role: Co-Principal Investigator Name: Dr. Kue Young Phone: 416-978-6459 E-mail: kue.young@utoronto.ca
Web site	www.inuithealthsurvey.ca

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): No specific screening question was used to identify Inuit community members. A list of Inuit residents in each community was generated based on community informants. Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached	
Question Design	Reason why the above question and/or identifier was chosen: Please describe	
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report:	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The Inuit Health Survey is the first comprehensive look at the health of Inuit in the Inuvialuit Settlement Region, Nunavut and Nunatsaivut. This study generated a dataset with rich possibilities for joint analyses and comparisons between neighbouring Inuit populations. Using a ship to visit remote and hard to reach communities, the survey provides a rich picture of health behaviours and status in these regions.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One Test /pilot/ evaluation report is available Select One Title/ citation for report:	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Funding for this project was received from the Government of Canada's Program for International Polar Year, Canadian Institutes for Health Research, Health Canada, University of Toronto, Inuvialuit Regional Corporation, Indian and Northern Affairs, and ArcticNet.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: The intent of the project is to repeat data collection every 7 years. Ongoing funding is a potential barrier to upcoming surveys.	

III. DATA ACCESS

Privacy Constraints	All work was approved by McGill's Institutional Review Board, the Aurora Research Institute and community corporations through community-university agreements. The study respected Inuit Qaujimajatuqangit, was conducted ethically and respected the confidentiality of each participant.
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☒ Collector of data ☐ Custodian ☒ Analyst ☒ User for decisions
	Community Research Assistants were hired in each participating community in the Inuvialuit Settlement Region, Nunavut and Nunatsiavut. In the weeks leading up to the Amundsen's arrival, Community Research Assistants began to recruit randomly selected households to take part in the Health Survey.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Yes Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications:
	Since the completion of data collection and data entry for the Adult Inuit Health Survey 2007-2008 and the Nunavut Inuit Child Health Survey, the primary activities have involved communication of results to communities, scientific conferences and community/ university workshops. In addition summary results from the Adult Inuit Health Survey have been sent to all participating communities, steering committees, Inuit organizations and funding agencies. A full report on the findings from the Inuivialuit Settlement Region can be found at the following link: www.irc.inuvialuit.com/publications/pdf/ihs-report-final.pdf
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions:
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes
	All adult and child participants received their personal results by mail after "Qanuqitpit? Qanuippitali? Kanuivit?" was completed. Communities received information on the health of their residents and about where health promotion efforts may be needed.

IV. DATA USE & REPORTING	
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification No Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	The most crucial steps in the development of the database were addressing issues related to the security and sustainability of the database, and maintaining the confidentiality of sensitive information.

5.1.3 Urban Aboriginal Peoples Study

I. DATABASE – Urban Aboriginal Peoples Study				
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	The Urban Aboriginal Peoples Study (UAPS) is a large, national study of First Nations, Métis and Inuit living in eleven urban centres across Canada. It is accompanied by a survey of the general public's attitudes toward Aboriginal peoples and issues. The study aims not to replicate past survey work, but rather explore new areas of inquiry concerning the factors currently leading Aboriginal peoples toward success, autonomy, cultural confidence and spiritual meaning. Topics included: urban Aboriginal peoples' communities of origin; Aboriginal cultures; community belonging; education; work; health; political engagement and activity; justice; relationships with Aboriginal and non-Aboriginal people; life aspirations and definitions of success; and experiences with discrimination. Previous studies have tended to view Aboriginal Canadians largely through a "problem lens" – that is, simply as targets for social services. The UAPS sought to fully capture urban Aboriginal peoples as complex individuals and communities. In doing so UAPS uncovered a broader range of narratives and scenarios than one typically encounters via the news and other media. To accomplish its aims, the UAPS included three separate research elements. First, 2,614 person-to-person interviews were conducted (the "Main" survey) with First Nations peoples (status and non-status), Métis and Inuit in 11 cities across Canada: Vancouver, Edmonton, Calgary, Regina, Saskatoon, Winnipeg, Thunder Bay, Montreal, Toronto, Halifax and Ottawa (Inuit only), between March and October 2009. Second, a telephone survey was conducted with 2,501 non-Aboriginal urban Canadians living in these same cities (excluding Ottawa) from April to May 2009. Finally, a pilot survey of 182 current and past National Aboriginal Achievement Foundation (NAAF) scholars was conducted on-line from June to July 2009.			
Custodian	Environics Institute			
	Mandate of Custodian: To survey people whose voices Canadians don't often hear			
Purpose	The study seeks to better understand and document the experiences, aspirations, values and identities of Aboriginal people living in Canadian cities.			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☐ program/service ☒ public policy	☒ Service Delivery ☐ enrolment/membership ☐ evaluation ☒ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☐ Aboriginal
	☒ Status (registered, treaty) ☒ Non-status ☐ On-reserve ☒ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
Status & Update	Database status Active	Database update frequency 1-off Frequency of Updates:		
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Mar-09	Month/year of latest available ethno-cultural identifiers: Oct-09		

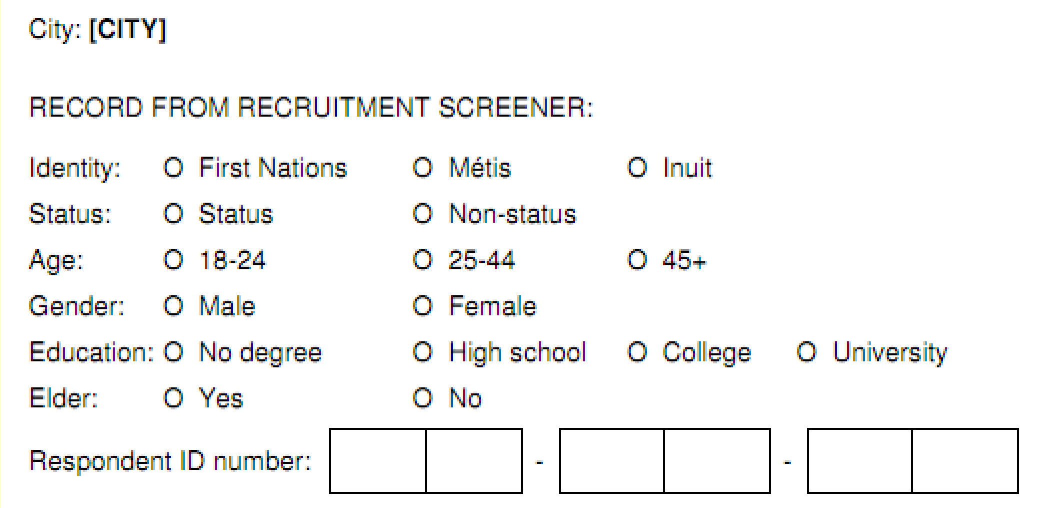
I. DATABASE – Urban Aboriginal Peoples Study

Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other 11 Canadian cities
	Municipality
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Aboriginal and non-Aboriginal researchers, policy makers, program administrators and the general public.
	Database also used by users external to Custodian
Populations	Population groups included in this database – 1) Métis, Inuit and First Nations (status and non-status) people living in 11 Canadian cities, 2) past recipients of National Aboriginal Achievement Foundation (NAAF) scholarships, 3) non-Aboriginal Canadians.
	Population Coverage - % of population targeted by the database that has been captured: N/A
	Alternatively, sample with weights? Yes. If yes, sample size A representative sample of more than 2,600 First Nations, Métis and Inuit peoples living in Canada's major cities.
Records	Total # of records in database: the UAPS involved 2,614 interviews with Métis, Inuit and First Nations (status and non-status) individuals living in eleven Canadian cities: Vancouver, Calgary, Edmonton, Regina, Saskatoon, Winnipeg, Thunder Bay, Toronto, Montreal, Halifax and Ottawa (Inuit only). These were conducted from March to October of 2009. This breaks down to 1,558 First Nations peoples, 789 Métis and 265 Inuit. Interviews with 182 NAAF scholars were also completed; the Environics Institute sees the NAAF study as a pilot that will lead to further research in the future. Finally, 2,501 non-Aboriginal Canadians were surveyed by phone on their attitudes toward Aboriginal people and issues.
	Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Environics Institute Title of person in support role: Executive Director Name: Keith Neuman, Ph.D. Phone: (613) 230.5089 E-mail: keith.neuman@environics.ca
Web site	www.uaps.ca

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s): From UAPS Main Survey - final Questionnaire April 7-2009:

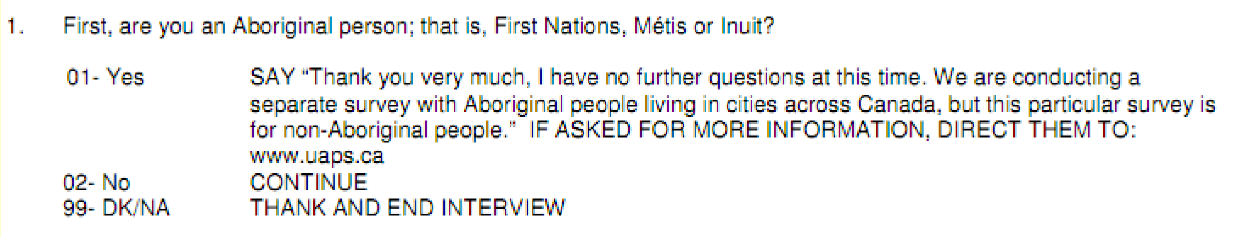


City: **[CITY]**

RECORD FROM RECRUITMENT SCREENER:

Identity: ○ First Nations ○ Métis ○ Inuit
Status: ○ Status ○ Non-status
Age: ○ 18-24 ○ 25-44 ○ 45+
Gender: ○ Male ○ Female
Education: ○ No degree ○ High school ○ College ○ University
Elder: ○ Yes ○ No
Respondent ID number: ☐☐ - ☐☐ - ☐☐

From UAPS Non-Aboriginal Survey – Final Questionnaire (April 29-2009):



1. First, are you an Aboriginal person; that is, First Nations, Métis or Inuit?

01- Yes	SAY "Thank you very much, I have no further questions at this time. We are conducting a separate survey with Aboriginal people living in cities across Canada, but this particular survey is for non-Aboriginal people." IF ASKED FOR MORE INFORMATION, DIRECT THEM TO: www.uaps.ca
02- No	CONTINUE
99- DK/NA	THANK AND END INTERVIEW

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached

Question Design

Reason why the above question and/or identifier were chosen: For the purposes of this study, the UAPS designed the research approach, and reports survey results, based on three Aboriginal "identity groups": First Nations, Métis and Inuit. UAPS participants identified themselves as belonging to one of these three groups. Nonetheless, it is important to recognize that the peoples captured in these three groups may consider themselves to be quite different from others in the same group. The categories "First Nations," "Métis" and "Inuit" encompass a tremendous amount of Aboriginal diversity that, while beyond the scope of the UAPS to fully capture, does exist.

Ethno-cultural identity question(s) has been tested Yes
Test report re question design is available No
Name/citation for test report: At each stage of questionnaire development, input was solicited from the Advisory Circle and study sponsors. Prior to the launch of the survey, the questionnaire was pilot tested by the Institute for Urban Studies at the University of Winnipeg (which also served as the local project team in Winnipeg for interviews conducted among First Nations peoples and Inuit). The pilot test consisted of interviews with a small sample of

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Aboriginal participants, conducted in the same manner as for the full survey. A small number of relatively minor questionnaire changes were implemented following feedback from the pilot test.
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Vancouver, Calgary, Edmonton, Saskatoon, Regina, Winnipeg, Thunder Bay, Toronto, Montreal, and Halifax participated in UAPS. These cities capture a large proportion of the urban Aboriginal population. These 10 cities have a total population of 286,000, representing 46% of the urban Aboriginal census population in Canada. Ottawa comprised the 11th city, and was added to include an important urban Inuit community. The geographic boundary for each city was defined as the Census Metropolitan Area (CMA), and excluded urban reserves. More than 100 interviewers, mostly Aboriginal, spoke, with 2,614 First Nations (status and non-status) peoples, Métis and Inuit living in the eleven Canadian cities. In-person interviews (1 – 2 hours+) were conducted with First Nations, Métis and Inuit living in the 11 cities. The study also interviewed non-Aboriginal people to better understand their views of Aboriginal people in Canada and Canadian cities today. A telephone survey was conducted in the spring of 2009 with 2,501 non-Aboriginal urban Canadians living in these same cities (excluding Ottawa). Finally, UAPS also encompasses a pilot study measuring the experiences and success in the lives of 182 National Aboriginal Achievement Foundation (NAAF) Scholars who have pursued or are pursuing post-secondary education. The research design of the main survey was guided by an Advisory Circle of recognized experts from academia and Aboriginal communities across Canada (see page 12 of this report for a list of UAPS Advisory Circle members). The Advisory Circle first met in September 2008 at the Forks in Winnipeg to discuss and agree on the broad focus and direction of the research. The main survey of urban Aboriginal peoples was originally conceived as a standard telephone survey with follow-up in-person interviews with a subset of participants, but the Advisory Circle felt in-person interviews would more effectively capture the full spectrum of the urban Aboriginal population (e.g., overlooking the homeless or those in shelters, or those with cell phones but no land line). In-person interviews also allow for a longer questionnaire length and for the establishment of rapport between interviewer and participant, ensuring a greater depth of information on a wide range of topics and greater comfort discussing potentially sensitive topics. Finally, Aboriginal culture may be characterized as an oral tradition, making interview-based data collection the most culturally-appropriate choice. As a result, in-person interviews were chosen as the sole methodology for the main survey. The Advisory Circle also developed the conceptual framework upon which the research is based. At its inaugural meeting, the Advisory Circle identified four themes – identities, experiences, values and aspirations – and a list of topics to be explored in the research. Based on this framework, Environics Research Group developed an initial content outline that addressed these themes and topics, followed by several drafts of the questionnaire. The questionnaire was designed to include both structured questions, to obtain quantifiable information, and open-ended questions, to capture greater depth and unprompted response to certain types of questions.
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No Test /pilot/ evaluation report is available Select One Title/ citation for report:
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 4. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	No
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	No
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality: It was important to capture voices from across the socio-economic spectrum, people with different levels of education, and people belonging to different identity groups (Métis, Inuit and First Nations). The UAPS research approach was designed to get as representative a picture as possible of Aboriginal men and women, those who identify as Inuit, Métis or First Nations, individuals with varying levels of education and all age groups. How UAPS achieved a representative sample: There is no sampling frame available for the urban Aboriginal population. To ensure as representative a sample of urban Aboriginal peoples as possible, the 2006 Census was used to construct a profile of Aboriginal people 18 years and older in each city, based on Aboriginal identity (First Nations, Métis, Inuit), age, gender and education. Based on the population profiles developed, quotas were established for all age, gender, education and identity groups in each city. To fill these quotas this study relied mainly on 'snowball' or network-based' sampling to identify participants, tactics typically used with populations that are hard to reach. Project coordinators and interviewers were also extremely resourceful and used a variety of methods to recruit participants, including posters, recruiting at Aboriginal events, telephone numbers for individuals to call if they wanted to participate, etc. This approach was ultimately successful in achieving a representative sample of Aboriginal peoples in most cities, and including hard-to-reach groups of Aboriginal peoples (such as individuals who are renting a room in a rooming house or hostel, or living in a temporary shelter, or who are homeless). How UAPS tried to reliably capture Aboriginal peoples' responses: The interviews were conducted in-person (not over the telephone, as is standard practice for most national research initiatives) by mainly Aboriginal interviewers. Each of the local research teams worked hard to create safe space for participants to speak freely and without fears of being judged. The success of this approach is demonstrated by the fact that many interviews went well beyond an hour in length and produced a rich and detailed set of responses from participants. Efforts were also made at the analysis stage to ensure open-ended responses (questions where participants could answer freely) were coded in a way that captured cultural nuances. An Aboriginal-owned and operated firm was retained to oversee this coding process. For further details on research methodology of the three component studies, see Chapter 1 of the report "The Urban Aboriginal Peoples Study" (2010).	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No This study reflects a very comprehensive effort to get the full picture that spans two years, with a multi-million dollar budget, a major volunteer effort and the substantial commitment of Environics staff and resources to make it happen.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Select One Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database

III. DATA ACCESS

Constraints

A Privacy Impact Assessment has been done for this database No

Information has been used for secondary purposes No
If yes, examples of secondary data use: Secondary analyses, e.g., driver analyses

First Nations, Inuit, and/or Métis Engagement

First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes
An MOU or formal agreement governing development and/or use of the database is in place No
First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as

☒ Designer (e.g. of question) | ☒ Collector of data | ☐ Custodian | ☒ Analyst | ☐ User for decisions

How the UAPS involved Aboriginal people in the project:
We made this an Aboriginal research project by bringing the following groups to the table:

- Aboriginal guides and experts (14 of our 19 Advisory Circle members are Aboriginal)
- Two Aboriginal project managers, and Aboriginal city supervisors (9 in 12 are Aboriginal)
- Aboriginal interviewers (a majority of our 116 interviewers are Aboriginal)
- Aboriginal organizations, agencies and Friendship centres (community collaborators)

To demonstrate respect for First Nations, Métis and Inuit peoples' reflections on their values, experiences, identities and aspirations, an Advisory Circle of recognized experts guided the design and interpretation of the study from academia and from the Aboriginal community.

The research design of the main survey was guided by an Advisory Circle of recognized experts from academia and Aboriginal communities across Canada. The Advisory Circle first met in September 2008 at the Forks in Winnipeg to discuss and agree on the broad focus and direction of the research.
The main survey of urban Aboriginal peoples was originally conceived as a standard telephone survey with follow-up in-person interviews with a subset of participants, but the Advisory Circle felt in-person interviews would more effectively capture the full spectrum of the urban Aboriginal population (e.g., overlooking the homeless or those in shelters, or those with cell phones but no land line). In-person interviews also allow for a longer questionnaire length and for the establishment of rapport between interviewer and participant, ensuring a greater depth of information on a wide range of topics and greater comfort discussing potentially sensitive topics. Finally, Aboriginal culture may be characterized as an oral tradition, making interview-based data collection the most culturally-appropriate choice. As a result, in-person interviews were chosen as the sole methodology for the main survey.
The Advisory Circle also developed the conceptual framework upon which the research is based. At its inaugural meeting, the Advisory Circle identified four themes – identities, experiences, values and aspirations – and a list of topics to be explored in the research.
Based on this framework, Environics Research Group developed an initial content outline that addressed these themes and topics, followed by several drafts of the questionnaire. The questionnaire was designed to include both structured questions, to obtain quantifiable information, and open-ended questions, to capture greater depth and unprompted response to certain types of questions.

Training and supporting mainly Aboriginal interviewers and city coordinators added a significant element of local capacity-building to the study. It also made participants feel more comfortable sharing their perspectives.

OCAP

The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:

First Nations OCAP principles No | Inuit Land Claims research protocols No | Métis requirements No

IV. DATA USE & REPORTING

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. http://uaps.ca/knowledge/ The UAPS main report is available here in English and French. In addition, there are City Reports and power point presentations for nine cities. 2. Sarah Roberton, Environics Research Group, “Drivers of self-perceived health among urban Aboriginal peoples” This paper draws on data from the Urban Aboriginal Peoples’ Study (UAPS) to achieve a better understanding of the factors associated with health among Aboriginal peoples living in urban settings. Previous research focuses largely on “risk factors” among individuals, families and environment, while the UAPS data permit investigation of “protective factors” at the individual and environment levels (e.g. self-esteem, sense of identity, sense of community). A multivariate regression (“driver”) analysis was conducted to determine the relative importance of these protective factors to urban Aboriginal peoples’ self-perceived health. The model was revisited by identity group, age and gender to determine if the same factors are equally at play for these population segments.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. Large communities of people have already been touched by this process — the Advisory Circle, our Aboriginal research partners, dozens of interviewers and coordinators in the eleven cities. Then, of course, there are the 2,614 First Nations, Métis, and Inuit people who took the time and exercised the generosity to talk to us. There are also the 182 National Aboriginal Achievement Foundation (NAAF) scholars, and the 2,500 non-Aboriginal Canadians who shared their perspectives. Many people have made this study happen; our responsibility now is to make sure that this information is shared with the greatest respect for those who offered it. Ideally, the things we have learned will help people understand each other better, have better conversations, and live together better in our urban communities. 2. Those who have worked on and supported the UAPS see the data as a powerful potential starting point for a range of initiatives: ongoing organizing and capacity-building in the cities studied; dialogue among Aboriginal networks and organizations about urban realities in different parts of the country; policy discussions at all levels of government; public dialogue; and, of course, further research. UAPS data will be made available to other research projects.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes The findings of the study are reported in a number of documents on www.uaps.ca, and are being released through UAPS media partners: the Aboriginal Peoples Television Network, the CBC, and The Globe and Mail. The Environics Institute also undertook an engagement process in the cities that participated in the study bringing the study’s findings back to the communities that shared their insights and told their stories. Prior to the public release of the report, Environics Institute presented the results to the national Aboriginal organizations (AFN, MNC, ITK, NWAC)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Other cities have expressed interest in having the UAPS take place in their community. For example, there is potential for a partnership between Environics Institute and the University of Saskatchewan to apply the UAPS model in Prince Albert.
	Thoughts/advice on factors that would <u>Support</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment <u>Limit</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment

IV. DATA USE & REPORTING

Additional Comments	Once the UAPS was underway, it was recognized that there was a significant opportunity to expand upon the standard reporting for this type of project by creating a video archive of the lives of urban Aboriginal peoples, as told in their own words. The Department of Indian/Native Communication Arts at First Nations University was commissioned to conduct 50 one-hour long video interviews with survey participants in each city, with the objective of bringing the study "to life" with the faces and voices of diverse individuals involved in the UAPS. This video archive is made available on the UAPS website www.uaps.ca.

5.0 Health Databases – National

5.2 ABORIGINAL AFFAIRS AND NORTHERN DEVELOPMENT CANADA

5.2.1 Indian Registry System

I. DATABASE – Indian Register	
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The Indian Register is the official record identifying all Registered Indians in Canada. Registered Indians are people who are registered with the federal government as Indians, according to the terms of the Indian Act. Registered Indians are also known as Status Indians.
Custodian	The Indian Registrar. The Office of the Indian Registrar is part of Aboriginal and Northern Affairs Canada (AANDC).
	Mandate of Custodian: Under the Indian Act, the Indian Registrar is responsible for maintaining the Indian Register. The Registrar is the sole authority for determining which names will be added, deleted or omitted from the Register. In order to determine who is entitled to be registered as a Status Indian, the Registrar must be able to confirm that the person is descended from people who were recognized as members of an Indian band. The Indian Act defines the categories of people who are eligible for registration as Indians.
Purpose	The Indian Register supports the following business functions: 1) Register eligible First Nations (FN) individuals as Registered Indians under the Indian Act in the Indian Register; 2) Record life events (e.g., birth, death, marriage, adoption, transfer of band membership, etc.) in the Indian Register; 3) Issue Certificates of Indian Status (Status Cards) to identify FN persons as eligible for services and benefits that are specifically designed for Registered Indians; 4) Renew or replace Certificates of Indian Status. Status Indians have certain rights and benefits that are not available to Non-Status Indians or Métis people. These may include on-reserve housing benefits, education and exemption from federal, provincial and territorial taxes in specific situations. They also include non-insured health benefits, a federal insurance program administered by the First Nations and Inuit Health Branch (FNIHB) at Health Canada. The Indian Register data that is collected by AANDC is provided to Health Canada First Nations and Inuit Health Branch through an MOU for use by NIHB.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data ☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☒ On-reserve ☒ Off-reserve ☒ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	The Indian Register contains the names of all Status Indians. It also has information such as dates of birth, death, marriage and divorce, as well as records of persons transferring from one band (or First Nation community) to another. This includes Status Indians on reserve and off reserve, in and outside of Canada. The registration of life events and the update of identity information are enabled through authorized secure on-line access to the Indian Registry System by government departments and Indian Registration Administrators (IRAs) in First Nation membership offices.
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: Daily
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1951 Month/year of latest available ethno-cultural identifiers: Aug-2011

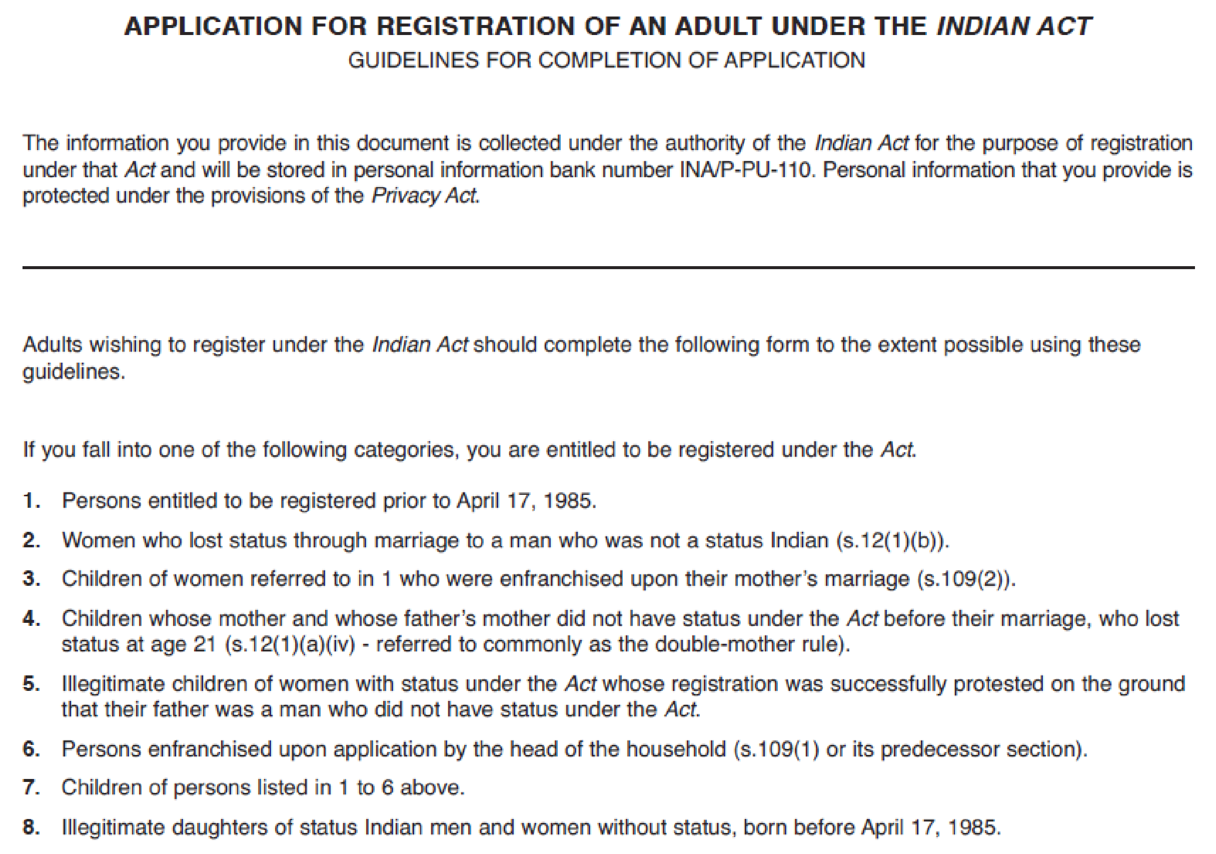
I. DATABASE – Indian Register

Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Band/ First Nation Select One
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Office of Indian Registrar/ AANDC, other government departments, Indian Registration Administrators (IRAs) in First Nation membership offices, qualified researchers who successfully complete an application process for Indian Registrar approval. Database also used by users external to Custodian
Populations	Population groups included in this database – All Indians registered under the Indian Act (Status Indians), as per the requirements of the Indian Act. Population Coverage - % of population targeted by the database that has been captured: The Indian Register captures 100% of active registered Indians. In addition, it contains records on people who are ancestors of registered Indians, who may be deceased and/or non-Indian. This is because the Indian Registry is an ancestry-based database; historical records may be used by First Nations people to build family trees (on-line). Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: ~ 850,000 active registered Indians as of October 2011; estimated ~ 860,000 active records by end November 2011. Annual number of records collected/updated: ~ 100,000 events (births, deaths, name changes, band transfers, etc.). This includes ~ 20,000 new registrants/ year: ~ 17,000 births in current or prior year, and ~ 3,000 registrants under Bills C-31 and C-3.
Contact/ Questions	Support Organization Office of the Indian Registrar Title of person in support role: Information Specialist Name: Andy Doraty Phone: 819-997-9265 E-mail: Andy.Doraty@aadnc-aandc.gc.ca
Web site	http://www.ainc-inac.gc.ca

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): The following link provides access to all forms related to programs and services offered by Aboriginal Affairs and Northern Development Canada (AANDC) that are related to benefits and rights for Aboriginal people - including Indian Registration: http://www.ainc-inac.gc.ca/eng/1100100032776/1100100032782. Selected key application details are presented below: Application for Registration of an Adult Under the Indian Act (Form No. Inter 83-044E, Version 2011-05-19):

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



APPLICATION FOR REGISTRATION OF AN ADULT UNDER THE *INDIAN ACT*

GUIDELINES FOR COMPLETION OF APPLICATION

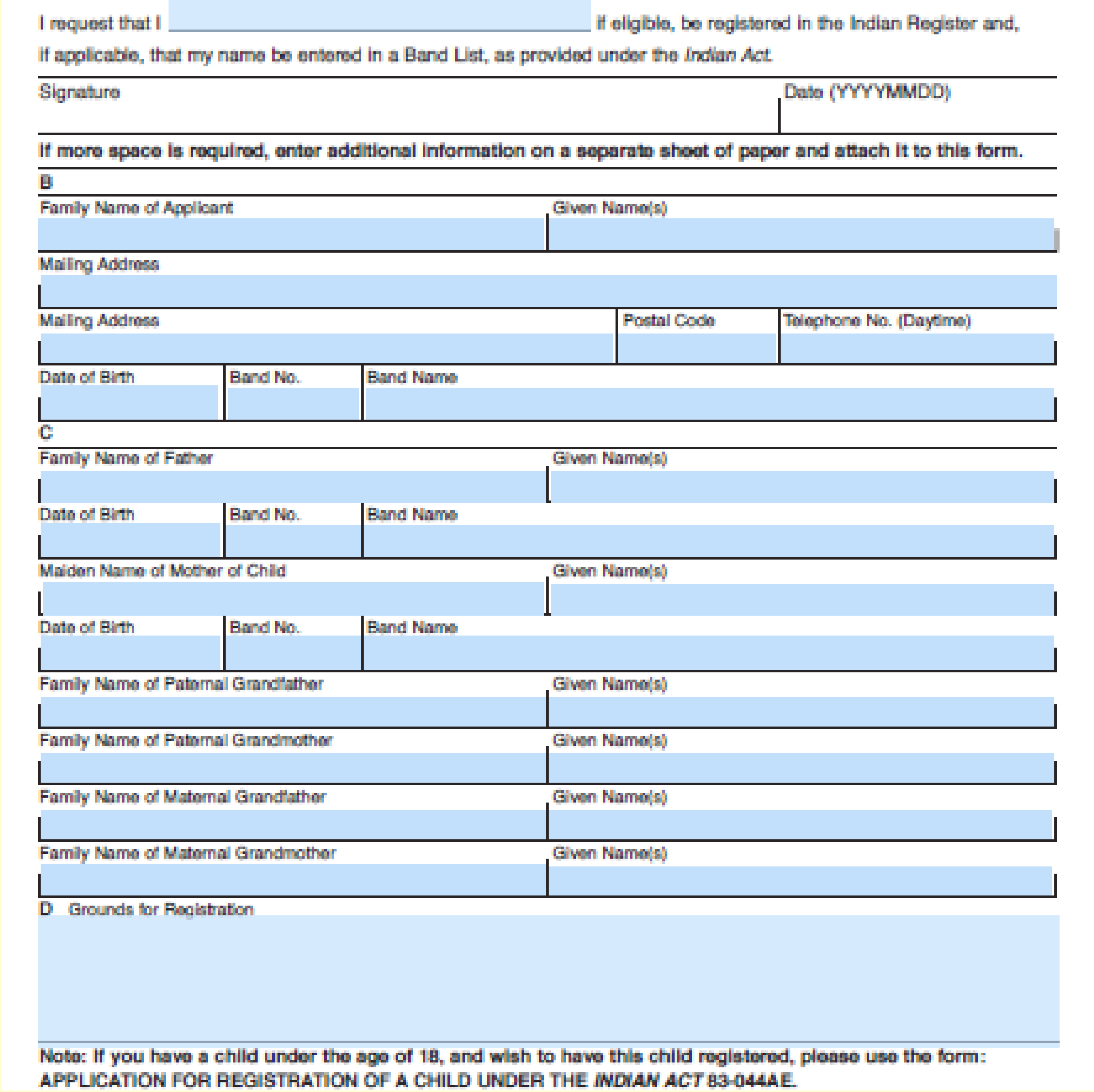
The information you provide in this document is collected under the authority of the *Indian Act* for the purpose of registration under that *Act* and will be stored in personal information bank number INA/P-PU-110. Personal information that you provide is protected under the provisions of the *Privacy Act*.

Adults wishing to register under the *Indian Act* should complete the following form to the extent possible using these guidelines.

If you fall into one of the following categories, you are entitled to be registered under the *Act*.

1. Persons entitled to be registered prior to April 17, 1985.
2. Women who lost status through marriage to a man who was not a status Indian (s.12(1)(b)).
3. Children of women referred to in 1 who were enfranchised upon their mother's marriage (s.109(2)).
4. Children whose mother and whose father's mother did not have status under the *Act* before their marriage, who lost status at age 21 (s.12(1)(a)(iv) - referred to commonly as the double-mother rule).
5. Illegitimate children of women with status under the *Act* whose registration was successfully protested on the ground that their father was a man who did not have status under the *Act*.
6. Persons enfranchised upon application by the head of the household (s.109(1) or its predecessor section).
7. Children of persons listed in 1 to 6 above.
8. Illegitimate daughters of status Indian men and women without status, born before April 17, 1985.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



I request that I ______________________ if eligible, be registered in the Indian Register and, if applicable, that my name be entered in a Band List, as provided under the *Indian Act*.

Signature	Date (YYYYMMDD)

If more space is required, enter additional information on a separate sheet of paper and attach it to this form.

B

Family Name of Applicant			Given Name(s)	
Mailing Address				
Mailing Address			Postal Code	Telephone No. (Daytime)
Date of Birth	Band No.	Band Name		

C

Family Name of Father			Given Name(s)
Date of Birth	Band No.	Band Name	
Maiden Name of Mother of Child			Given Name(s)
Date of Birth	Band No.	Band Name	
Family Name of Paternal Grandfather			Given Name(s)
Family Name of Paternal Grandmother			Given Name(s)
Family Name of Maternal Grandfather			Given Name(s)
Family Name of Maternal Grandmother			Given Name(s)

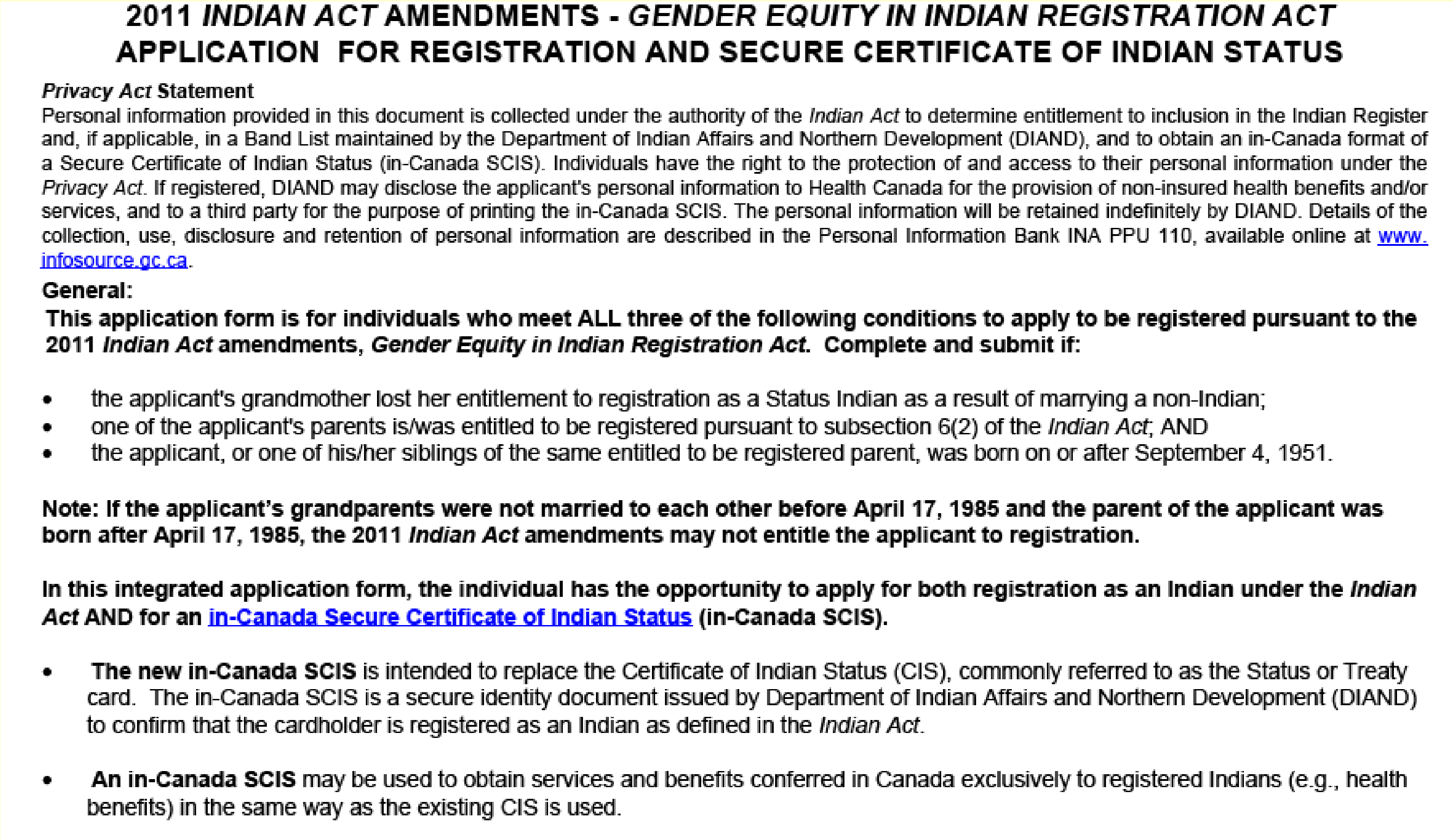
D Grounds for Registration

Note: If you have a child under the age of 18, and wish to have this child registered, please use the form: APPLICATION FOR REGISTRATION OF A CHILD UNDER THE *INDIAN ACT* 83-044AE.

Indian Registration for Bill C-3 applicants (2011 Indian Act amendments - Gender Equity in Indian Registration Act - Application for Registration and Secure

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Certificate of Indian Status (Form No. Inter 83-114E, Version 2011-01-31). This application also includes a Guarantor Declaration (not presented here).



2011 *INDIAN ACT* AMENDMENTS - *GENDER EQUITY IN INDIAN REGISTRATION ACT*
APPLICATION FOR REGISTRATION AND SECURE CERTIFICATE OF INDIAN STATUS

***Privacy Act* Statement**

Personal information provided in this document is collected under the authority of the *Indian Act* to determine entitlement to inclusion in the Indian Register and, if applicable, in a Band List maintained by the Department of Indian Affairs and Northern Development (DIAND), and to obtain an in-Canada format of a Secure Certificate of Indian Status (in-Canada SCIS). Individuals have the right to the protection of and access to their personal information under the *Privacy Act*. If registered, DIAND may disclose the applicant's personal information to Health Canada for the provision of non-insured health benefits and/or services, and to a third party for the purpose of printing the in-Canada SCIS. The personal information will be retained indefinitely by DIAND. Details of the collection, use, disclosure and retention of personal information are described in the Personal Information Bank INA PPU 110, available online at www.infosource.gc.ca.

General:

This application form is for individuals who meet ALL three of the following conditions to apply to be registered pursuant to the 2011 *Indian Act* amendments, *Gender Equity in Indian Registration Act*. Complete and submit if:

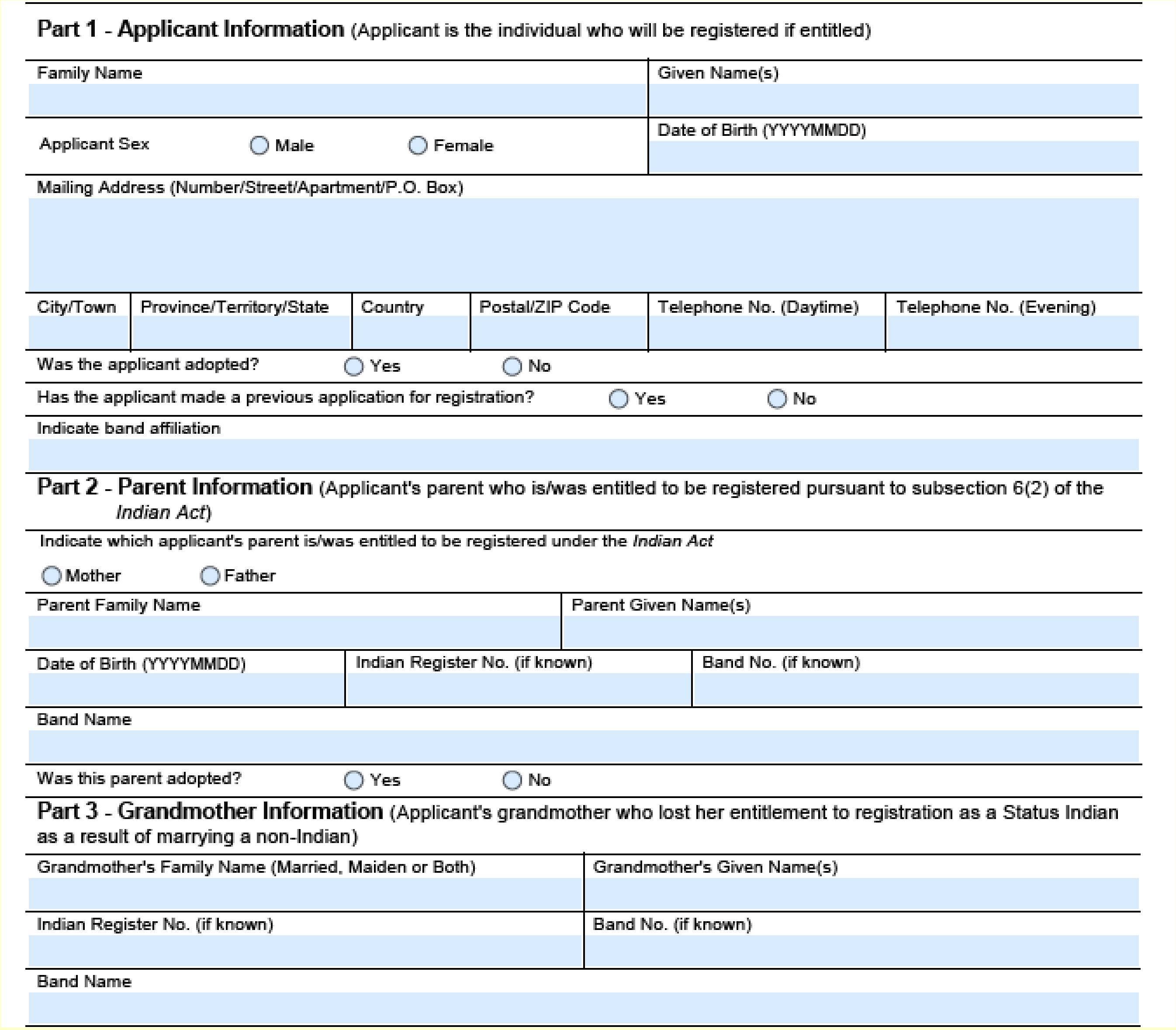
- the applicant's grandmother lost her entitlement to registration as a Status Indian as a result of marrying a non-Indian;
- one of the applicant's parents is/was entitled to be registered pursuant to subsection 6(2) of the *Indian Act*; AND
- the applicant, or one of his/her siblings of the same entitled to be registered parent, was born on or after September 4, 1951.

Note: If the applicant's grandparents were not married to each other before April 17, 1985 and the parent of the applicant was born after April 17, 1985, the 2011 *Indian Act* amendments may not entitle the applicant to registration.

In this integrated application form, the individual has the opportunity to apply for both registration as an Indian under the *Indian Act* AND for an in-Canada Secure Certificate of Indian Status (in-Canada SCIS).

- **The new in-Canada SCIS** is intended to replace the Certificate of Indian Status (CIS), commonly referred to as the Status or Treaty card. The in-Canada SCIS is a secure identity document issued by Department of Indian Affairs and Northern Development (DIAND) to confirm that the cardholder is registered as an Indian as defined in the *Indian Act*.
- **An in-Canada SCIS** may be used to obtain services and benefits conferred in Canada exclusively to registered Indians (e.g., health benefits) in the same way as the existing CIS is used.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



Part 1 - Applicant Information (Applicant is the individual who will be registered if entitled)

Family Name	Given Name(s)
Applicant Sex ○ Male ○ Female	Date of Birth (YYYYMMDD)

Mailing Address (Number/Street/Apartment/P.O. Box)

City/Town	Province/Territory/State	Country	Postal/ZIP Code	Telephone No. (Daytime)	Telephone No. (Evening)

Was the applicant adopted? ○ Yes ○ No

Has the applicant made a previous application for registration? ○ Yes ○ No

Indicate band affiliation

Part 2 - Parent Information (Applicant's parent who is/was entitled to be registered pursuant to subsection 6(2) of the *Indian Act*)

Indicate which applicant's parent is/was entitled to be registered under the *Indian Act*

○ Mother ○ Father

Parent Family Name	Parent Given Name(s)	
Date of Birth (YYYYMMDD)	Indian Register No. (if known)	Band No. (if known)

Band Name

Was this parent adopted? ○ Yes ○ No

Part 3 - Grandmother Information (Applicant's grandmother who lost her entitlement to registration as a Status Indian as a result of marrying a non-Indian)

Grandmother's Family Name (Married, Maiden or Both)	Grandmother's Given Name(s)
Indian Register No. (if known)	Band No. (if known)

Band Name

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design	Reason why the above question and/or identifier were chosen: Application for Indian Registration is governed by the Indian Act.	
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report: Not applicable	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The Indian Register represents a source of information that - within the strict legislative requirements for individual privacy, confidentiality and security, and at the discretion of the Indian Registrar - may be used for the public good to improve information that supports better knowledge and decisions regarding e.g. health status among the First Nation peoples.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No Test /pilot/ evaluation report is available No Title/ citation for report: Not applicable	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Completeness, accuracy and timeliness of records/ updates	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes
	Title/citation for test/pilot/quality evaluation report:	
	The most significant initiative that is expected to improve the quality and timeliness of the information in the Indian Registry is the roll-out of new secure Indian Status cards over the next 5 years. This is expected to improve information categories like residency, and major life events, as the card will be renewed every 5 years. Currently, the Registry contains records that have not been updated since they were first entered, which in some cases may be > 30 years ago. Obviously, that means that e.g. residency information will often be out of date, due to migration. Other initiatives that can have a positive effect on quality are related to removing barriers to complete and timely information about births. For example, new approaches enabled by the B.C. Tripartite agreement, that involve waiving the cost of birth certificates for First Nations people, and sharing the data directly from source between the B.C. Vital Statistics Agency and the Indian Registry, can result in better, more timely data. It is currently not uncommon that new births take at least 1 - 2 years to be registered.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No The Indian Act legislates the existence of the Indian Register and its mandate.	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: 1) Registration as a Status Indian requires a detailed application process; 2) The key issues are around accurate and timely documentation of residency and life events information; these in turn are affected by i) a high annual volume of 100,000 events (changes, additions) in the Register, ii) a large number (> 485) of Indian Registry Administrators who all work in their own unique environment on 550 First Nations across the country, and iii) barriers to timely registration/ information updates faced by First Nations people themselves, e.g. remoteness, cost of travel/ birth certificates, lack of perceived need, etc.

III. DATA ACCESS

Privacy Constraints	The Indian Registry is subject to the legislative requirements of 1) the Indian Act, and 2) all applicable federal and provincial/territorial legislation regarding the protection of individual privacy, confidentiality and security, e.g., the Access to Information Act which gives Canadian citizens the right to access information in federal government records, and the Privacy Act which provides citizens with the right to access personal information held by the government and protection of that information against unauthorized use and disclosure.
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: 1) as part of the BC Tripartite Agreement - to improve information that supports planning and tracking initiatives agreed under the Agreement; 2) data linkage for studies to assess the burden of cancer among First Nations in various provinces, e.g. Manitoba, Ontario.
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Select One An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☒ Collector of data ☐ Custodian ☒ Analyst ☒ User for decisions
	While the Indian Act is the key determinant of the existence of the Indian Register, First Nations people and communities have active roles in the administration and use of the data. 550 of the 616 Indian Bands across Canada employ Indian Register Administrators (IRA) who performs registry functions on reserve on behalf of the Indian Registrar: administration and documentation of births, marriages, name changes, deaths, band transfers, etc.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols Not Applicable Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. The Office of the Indian Registrar/ AANDC conducts a wide range of research and analyses regarding Aboriginal topics. An overview of research reports, statistics and other publications can be found at www.aandc.gc.ca 2. Linkage projects to assess the burden of disease, e.g., cancer, on First Nations have been done in a number of provinces and territories.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. Initiatives ranging from improvements to how data gets collected and used, to decisions to change policy in the administration of First Nations programs. 2. Initiatives to put a higher level of funding and accountability against initiatives to address inequitable health outcomes.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Typically, the information has been shared at the provincial level by groups that include (provincial) representatives of First Nations, AANDC, FNIHB, and researchers.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification No The Indian Register is a unique national register, emanating from the requirements of the Indian Act.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Limit the re-application of this ethno-cultural identification approach to other jurisdictions:
Additional Comments	Of note, "Band Membership" and "Indian Status" are two different things. Indian Status is determined by a process overseen by the Office of the Indian Registrar. Band Membership is determined by a process overseen by an individual Band or First Nation. For example, a person can be a "Status Indian" without being a member of a band.

5.0 Health Databases – National

5.3 CANADA HEALTH INFOWAY

5.3.1 Electronic Medical Record: Ethnicity Reference Set

I. DATABASE – Electronic Medical Record: Ethnicity Reference Set

Geography	☒ Canada ☒ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	THIS IS NOT A DATABASE, BUT A N ETHNICITY REFERENCE SET, I.E., A VALUE SET THAT SUPPORTS THE CIHI LED PAN-CANADIAN PRIMARY HEALTH CARE CONTENT STANDARD (PHC CS). THIS WILL FACILITATE CONSISTENCY IN THE WAY ETHNICITY IS CAPTURED IN CANADIAN ELECTRONIC MEDICAL RECORDS. THIS ETHNICITY REF SET IS AT THE DRAFT STAGE AS OF NOVEMBER 8, 2010. THE GOAL IS TO COMPLETE DEVELOPMENT BY FEBRUARY 2012. The PHC-CS includes 106 data elements, 53 of which (including 'ethnicity') require standardized terminology. For more information about the PHC-CS, SEE https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC1587&lang=en
Custodian	The development of an Ethnicity Reference Set has been led by Canada Health Infoway in collaboration with CIHI to support the PHC CS.
	Mandate of Custodian: For the purpose of this project: to develop standardized terminology for the pan-Canadian PHC CS.
Purpose	The development of a Reference Set for ethnicity aims to address the current lack of a consistent approach to the collection of ethnicity data in Canadian medical records. The objective is to create value sets that support consistent data collection and extraction from EMRs. The content standard will support primary (clinician frontline) and secondary (health system) use. There are two Ethnicity Data Elements (A13 and E10) that need Ethnicity RefSets. The Ethnicity RefSets for A13 and E10 will likely be the same.

#	Common Refset Name	Name	Refset Definition
A13	Patient Ethnicity	Client Administrative Ethnicity Code	Represents the Client's self-reported ethnic group to which he or she belongs, for administrative purposes. Therefore, the ethnic origin refers to a person's "roots" and should not be confused with his or her citizenship or nationality.
E10	Family Member Ethnicity	Observation Family History Familial Ethnicity Code	Represents the ethnicity of the family member.

☒ Public Health & Surveillance
- ☒ screening
- ☒ immunization
- ☒ communicable disease
- ☐ other Specify

☒ Operating a Health Organization or System
- ☐ funding & reimbursement
- ☐ transactions, e.g. drug dispensing
- ☒ capacity & utilization planning
- ☒ performance mgmt. & accountability

☒ Research
- ☒ population
- ☒ clinical
- ☒ program/service
- ☒ public policy

☒ Service Delivery
- ☐ enrolment/membership
- ☒ evaluation
- ☒ equity
- ☒ patient navigation

I. DATABASE – Electronic Medical Record: Ethnicity Reference Set

Demographics	☒ Database includes demographic data ☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	This is not a database. The EMR-PHC Ethnicity Reference Set defines the values for the data required to provide consistency to ethnic identification in electronic medical records. For details on the values for Aboriginal identification, see section II.
Status & Update	Database status Select One Database update frequency Select One Frequency of Updates: N/A
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): implementation of the standard is targeted to start in 2012. Month/year of latest available ethno-cultural identifiers: N/A
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☒ Primary Care ☒ Immunization ☐ Mental Health/Addictions ☒ Drugs ☒ Communicable Disease
Users	Primary users of this database - This reference set should be applied by agencies and clinicians responsible for the delivery of services and programs in the areas of primary care and public health.
	Database also used by users external to Custodian
Populations	Population groups included in this database – The databases supported by the PHC-CS, which would include a RefSet for Ethnicity, would encompass all patients/ clients served by an agency (e.g. public health agency) and/or clinician (e.g. primary care physician) who has adopted the EMR-CS and its associated 53 Reference Sets.
	Population Coverage - % of population targeted by the database that has been captured: Not applicable yet, as this RefSet has not been implemented yet. The objective would be 100% coverage.
	Alternatively, sample with weights? No. If yes, sample size % of population
Records	Total # of records in database: N/A Annual number of records collected/updated: N/A
Contact/ Questions	Support Organization Canada Health Infoway Title of person in support role: Project Director, Emerging Technologies Group Name: Sukhi Burgen Phone: 416-595-3171 E-mail: sburgen@infoway-inforoute.ca
Web site	www.infoway-inforoute.ca for Standards Collaborative info on SNOMED CT Reference Sets; www.cihi.ca for information on the PHC-EMR Content Standard (CS)

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s): Below are the Values that have been developed for Aboriginal identification. The entire Ethnicity RefSet comprises several hundred ethnicities. Of note, the latter happens because SNOMED CT is an international system for medical terminology, so the ethnicity values are used in many countries world-wide.

Referenced Code	Concept Name	En preferred Term
extension required	First Nations (ethnic group)	First Nations
extension required	Inuit (ethnic group)	Inuit
extension required	Métis (ethnic group)	Métis

Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier were chosen: The approach to Reference Set development is to "adopt, adapt or develop". The Standards Collaborative Working Group for the EMR Project (SCWG 1) performed an environmental scan that included reviews of the standards used by Statistics Canada and SNOMED CT (see "Additional Comments" below for a brief backgrounder on SNOMED CT). The SCWG for Public Health and Primary Care decided to use the ethnicity hierarchy in SNOMED CT (which is an international standard) - complemented by key terms used by Statistics Canada in its surveys, specifically the addition of "First Nations", "Inuit" and "Métis". The development process also included clinician review and validation.

Ethno-cultural identity question(s) has been tested Yes
Test report re question design is available Yes
Name/citation for test report: The extensive testing Statistics Canada has done for the Census Long Form and Aboriginal Peoples Survey; see citations in the Profiles for Census Long Form and Aboriginal Peoples Survey.

- The data identified through this standard is consistent with the Census denominators which allow for National /Provincial/Territorial comparisons.
- Statistics Canada has adopted the Census questions as a standard way of identifying Aboriginal groups on other surveys, such as the Aboriginal Peoples' Survey.

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: This is the first time a pan-Canadian value set for First Nations, Inuit and Métis identification has been set; the Content Standard, and associated Data Elements with their individual Reference Sets will affect data collection for future electronic medical records. Specifically:

- The adoption of a pan-Canadian ethnicity reference set (including Aboriginal identifiers) helps ensure that information collected is complete, comparable and useful for planning and reporting purposes.
- A common definition of the First Nations, Inuit and Métis populations will enhance inter-jurisdictional coordination across program areas.
- The information identified through this reference set is consistent with the Census denominators which allow for National /Provincial/Territorial comparisons.
- Statistics Canada has adopted the Census questions as a standard way of identifying Aboriginal groups on other surveys, such as the Aboriginal Peoples' Survey. This information can be used to supplement electronic medical record information.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Yes
Test /pilot/ evaluation report is available Yes
Title/ citation for report: See comments above, under Question Design.
Of note, the process for developing, maintaining and updating Reference Sets includes a "Request for Change" process to accommodate additional

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	concepts. Therefore, it is possible to generated identifiers that are not in SNOMED CT, but can be shown to be important to support the ultimate objective of standards: better patient care. These additional identifiers would be "Canadian extensions" to the existing RefSet, and first have to pass a Canadian review process to be included in the Canadian value set. There is no limit on the number of terms that can be included in a Reference Set. Lastly, it is possible to request the addition of "Local extensions". This is generally not promoted, as it impedes the interoperability of electronic medical records.	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Select One 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality (optional): The key criteria for terms (values) in a Reference Set are that they must be reproducible, useful and understandable.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes Paying for surveys and access to special data sets is expensive. Migration to this standard will entail costs (financial and human resources) but once established will provide an inexpensive source of data that can be used for the above stated purposes.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: Implementation of the EMR is a resource-intensive, multi-year process. Implementation of the RefSet is scheduled to start in 2012. Canada Health Infoway implementation support will extend into 2013.	

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database: N/A
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use: The information that results from application of the Ethnicity RefSet will support primary (clinician/ frontline) and secondary (health system) use.
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional):

III. DATA ACCESS

OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions No Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes The purpose of the project is to develop a pan-Canadian data standard for ethnicity in EMRs. Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	SNOMED CT (Systematized Nomenclature of Medicine -- Clinical Terms), is a systematically organised computer processable collection of medical terminology covering most areas of clinical information such as diseases, findings, procedures, microorganisms, substances, etc. It allows a consistent way to index, store, retrieve, and aggregate clinical data across specialties and sites of care. It also helps organising the content of medical records, reducing the variability in the way data is captured, encoded and used for clinical care of patients and research. The primary purpose of SNOMED CT is to support the effective clinical recording of data with the aim of improving patient care. It is a structured collection of medical terms that are used internationally for recording clinical information and are coded in order to be computer processable. It covers areas such as diseases, symptoms, operations, treatments, devices and drugs. Its purpose is to consistently index, store, retrieve, and aggregate clinical data across specialties and sites of care. It helps organizing the content of electronic health records systems, reducing the variability in the way data is captured, encoded and used for clinical care of patients and research. Specific language editions are available which augment the International Edition and can contain language translations as well as additional national terms. SNOMED CT is considered by some to be the most comprehensive, multilingual clinical healthcare terminology in the world. It provides for consistent information interchange and is fundamental to an interoperable electronic health record. It can be used to record the clinical details of individuals in electronic patient records and support application functionality such as informed decision making, linkage to clinical care pathways and knowledge resources, shared care plans and as such support long term patient care. http://en.wikipedia.org/wiki/SNOMED_CT accessed 11/11/11.

5.0 Health Databases – National

5.4 CANADIAN INSTITUTE FOR HEALTH INFORMATION

5.4.1 Canadian Organ Replacement Register

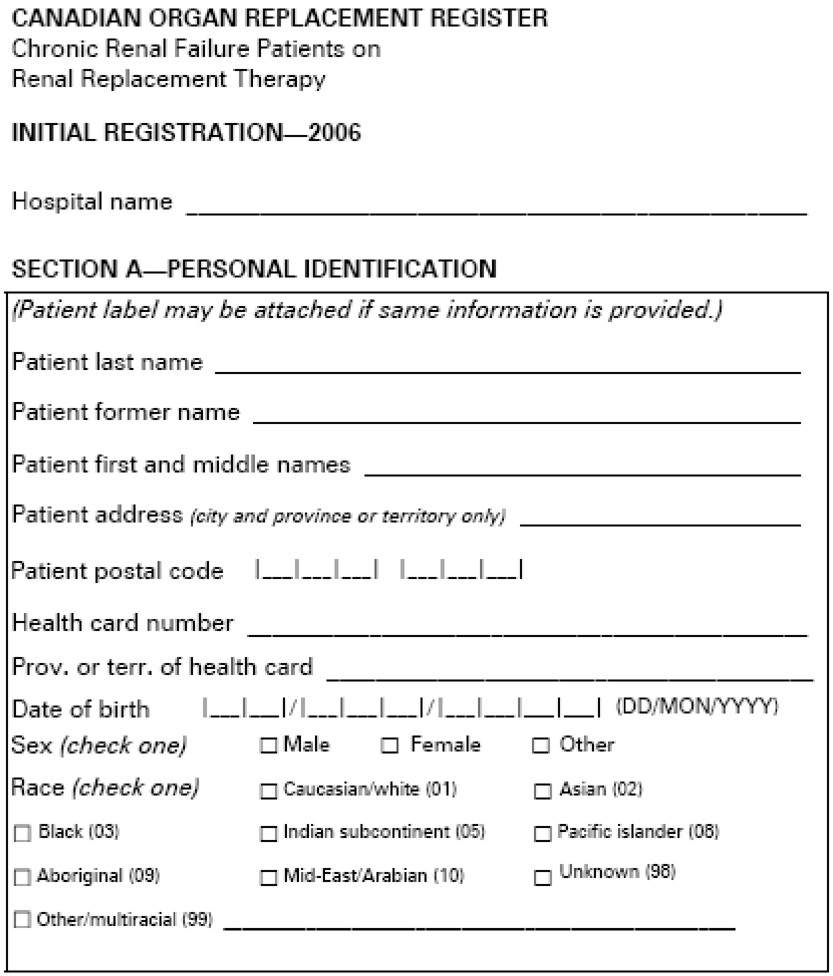
I. DATABASE – Canadian Organ Replacement Register	
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NV ☐ Other Specify
Description	The Canadian Organ Replacement Register (CORR) records, analyzes and reports on the level of activity and outcomes of vital organ transplantation and renal dialysis activities in Canada
Custodian	Canadian Institute for Health Information (CIHI)
	Mandate of Custodian: Provide pan-Canadian information on end-stage organ failure in Canada, with the goal of enhancing treatment, research and patient care.
Purpose	1) provide national view on end-stage organ failure statistics for comparative analyses & research studies, 2) facilitate better treatment decisions, 3) planning & optimizing programs, 4) mechanism for facility feedback, quality assurance, and national standard for comparison.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☐ equity ☒ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☒ Aboriginal ☐ Other Specify
	CORR collects data from Hospital Dialysis Programs, Regional Transplant Programs, Organ Procurement Organizations and independent Kidney Dialysis Service Facilities via standardized paper forms or spreadsheets. Aboriginal is captured as part of an ethno-cultural identity question. CORR has captured a race field since inception. The current coding has been in place since 2002.
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: Annual (calendar year)
Availability	Month/year of earliest available ethno-cultural identifiers: 1981 (e.g. FEB-98) Month/year of latest available ethno-cultural identifiers: 2011
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code

I. DATABASE – Canadian Organ Replacement Register

Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☒ Renal Dialysis ☐ Immunization ☐ Communicable Disease	
Users	Primary users of this database - Program managers, clinicians, system administrators, policy makers, researchers and funders	
	Database also used by users external to Custodian	
Populations	Population groups included in this database – All patients who have received extra-renal organ transplant since 1-1-1988, and all chronic renal failure patients who have initiated RRT since 1-1-1981.	
	Population Coverage - % of population targeted by the database that has been captured: There are no known coverage errors within CORR: estimated at close to 100% of transplant and renal dialysis patients.	
	Alternatively, sample with weights? No. If yes, sample size	
Records	Total # of records in database: 110,000 with approximately 50,000 active records; In 2009, there were ~ 1,800 active patients in CORR who were identified as Aboriginal.	Annual number of records collected/updated: Approximately 6000 new patients added each year, with 50,000 living on dialysis or with a functioning transplant
Contact/ Questions	Support Organization CIHI Title of person in support role: Program Lead Name: Bob Williams Phone: 416-549-5383 E-mail: rwilliams@cihi.ca	
Web site	http://www.cihi.ca	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question



CANADIAN ORGAN REPLACEMENT REGISTER
Chronic Renal Failure Patients on
Renal Replacement Therapy

INITIAL REGISTRATION—2006

Hospital name ____

SECTION A—PERSONAL IDENTIFICATION

(Patient label may be attached if same information is provided.)

Patient last name ____

Patient former name ____

Patient first and middle names ________________________________

Patient address *(city and province or territory only)* ____________________

Patient postal code |___|___|___| |___|___|___|

Health card number ____

Prov. or terr. of health card ____________________________________

Date of birth |___|___|/|___|___|___|/|___|___|___|___| (DD/MON/YYYY)

Sex *(check one)* ☐ Male ☐ Female ☐ Other

Race *(check one)* ☐ Caucasian/white (01) ☐ Asian (02)

☐ Black (03) ☐ Indian subcontinent (05) ☐ Pacific islander (08)

☐ Aboriginal (09) ☐ Mid-East/Arabian (10) ☐ Unknown (98)

☐ Other/multiracial (99) ____

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design	Reason why the above question and/or identifier were chosen: No record exists of the exact rationale; pre-2002 separate categories for First Nations and Inuit were replaced by a (possibly) more inclusive category of Aboriginal.	
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report:	
Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Aboriginal peoples have high diabetes rates which in turn are related to a high rate of diabetic nephropathy. Systematic collection of valid and comparable data on ESRD progression, RRT outcomes and associated socio-economic and cultural factors affecting onset, treatment and outcomes are the necessary foundation for policy and program improvements.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluate No Test/pilot/evaluation report is available No Title/citation for report:	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	No
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Agreement rates for patient race (Recoding Study, 2009); non-response/unknown values for race/ethnic origin related to donors, transplant recipients, and incident dialysis patients in CORR by year and province.	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes
	Title/citation for test/pilot/quality evaluation report: Data Quality Study on the Canadian Organ Replacement Register, CIHI, July 2009	
	Data Quality Study (2009) found that 3 of 4 demographic data elements that are frequently used in CORR analysis (health card number, date of birth, sex) were very reliable, with agreement rates exceeding 97%. Lower agreement was observed for patient's race (58%); but agreement rate was highest for Aboriginal (87.3%). Discrepancies typically traced to Unknown codes reported: 10.3% for Aboriginal versus 45.4% for Caucasian/white.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: Consistent collection and recording of ethno-cultural identifiers by busy frontline staff: Data Quality Study (2009) found that frontline staff in dialysis units completing CORR forms utilized multiple methods for determining race: medical chart extraction (49%), asking patients (68%), inference from appearance (42%), language (22%), name (18%), and deducing race from physical description recorded by nephrologist (32%). More specific guidelines in the CORR Instruction Manual would improve the recording of this information. User instructions related to race are as follows:	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Race

- Indicate the patient's race.
- Only one response can be checked.
- If race is "other/multiracial," specify.
- Acceptable values:

01 = Caucasian/white (French Canadians and other peoples of European, Australian or Russian ancestry)
02 = Asian (Chinese, Japanese, Vietnamese, Korean, Taiwanese)
03 = Black (African, Jamaican, Haitian, Somali)
05 = Indian subcontinent (peoples of India, Pakistan, Bangladesh)
08 = Pacific Islander (Filipino)
09 = Aboriginal (North American Indian, Métis, Inuit)
10 = Mid-East/Arabian (peoples of Saudi Arabia, Iran, Iraq, Algeria, Jordan, Syria, Armenia)
11 = Latin American (Caribbean, South American, Cuban)
98 = Unknown
99 = Other/multiracial ____________

III. DATA ACCESS

Privacy Constraints	The protection of individual privacy, the confidentiality of records and the security of information are essential to CIHI. In support of this, CIHI has in place a comprehensive and integrated privacy and security program. A key element of CIHI's privacy and security program is CIHI's Privacy Policy, 2010, which sets out the rules on the collection, use, disclosure, retention and destruction of personal health information and de-identified data.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: Clinical measures for patient management; distance to treatment; survival analysis; differences in treatment modalities
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols No Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Survival of patients by selected demographic factors. 2. Counts of incident and prevalent patients by race. 3. Canadian Organ Replacement Register Annual Report, CIHI, January 2011. 4. CORR, Data Quality Study on the Canadian Organ Replacement Register, CIHI, July 2009
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. Research has been conducted that looks at distance and access to treatment based on ethno-cultural identifiers; this research demonstrates how distance from a dialysis centre can improve outcomes. 2. A full bibliography of literature, and associated recommendations, based on the CORR database - including studies specifically done with and for Aboriginal peoples - is available at http://www.cihi.ca/CIHI-ext-portal/internet/en/document/types+of+care/specialized+services/organ+replacements/services_corr_research
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Comments on communication approach used and response (optional): The CORR board, which is responsible for providing strategic advice to the register, includes nephrology and transplant clinicians who work closely with the Aboriginal communities. Also, CIHI has a dedicated First Nations, Inuit and Métis group who work closely with community-based health advisory groups.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification No Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: It is a useful general indicator for identifying scope and potential differences among ethno-cultural groups. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: The current collection method does not allow for the identification of sub groups within Aboriginal. Probabilistic approaches using census data and patient postal codes have been suggested, but not tried
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

5.4.2 Continuing Care Reporting System

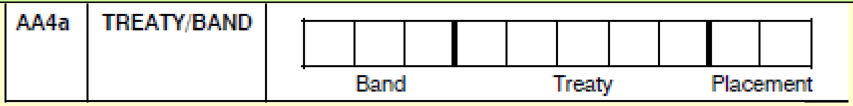
I. DATABASE – Continuing Care Reporting System				
Geography	☐ Canada ☒ BC ☐ AB ☒ SK ☒ MB ☒ ON ☐ QC ☐ NB ☒ NS ☐ PE ☒ NL ☒ YT ☐ NT ☐ NV ☐ Other Specify			
Description	The Continuing Care Reporting System (CCRS) contains demographic, clinical, functional and resource utilization information on individuals receiving continuing care services in hospitals or long-term care homes in Canada, in jurisdictions that participate in the CCRS. Participating organizations also provide information on facility characteristics to support comparative reporting and benchmarking.			
Custodian	Canadian Institute for Health Information (CIHI)			
	Mandate of Custodian: Work with stakeholders to create and maintain a broad range of health databases, measurements and standards that provide essential information on Canada's health system and the health of Canadians.			
Purpose	The interRAI Resident Assessment Instrument Minimum Data Set (RAI-MDS 2.0)© is used to identify the preferences, needs and strengths of continuing care hospital patients or long-term care home residents and provides a snapshot of their services. The information, gathered electronically at the point of care, provides real-time decision support for front-line care planning and monitoring. The RAI-MDS 2.0 is the assessment contained within the CCRS. The purpose of the Continuing Care Reporting System is to: • collect, process and analyse data on continuing care residents in Canada • support management decision-making at the facility, regional and provincial/territorial levels • support the development and use of case-mix and resource utilization grouping methodologies • facilitate facility, regional, provincial/territorial and national comparative reporting • support related approved analysis and research			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify	☒ Operating a Health Organization or System ☒ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☒ equity ☒ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☒ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	The question underlying this information is expected to be changed in 2012-2013 to: "Client identifies self as First Nations (yes, no), Métis (yes, no), Inuit (yes, no).			
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates: Sixty days following the end of the quarter, a data cut of the submitted data is used for the creation of the CCRS eReports		
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 2003/04 (data from hospital based continuing care goes back to 1995) Month/year of latest available ethno-cultural identifiers: 2011			

I. DATABASE – Continuing Care Reporting System

Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Reversible	
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify	
	Postal Code	
Service Domain	☐ Acute Care ☐ Emergency Care ☒ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☒ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease	
Users	Primary users of this database - The information is designed to inform decision-making by health care professionals and continuing care administrators, as well as system planners and policy-makers at local, regional and provincial levels. The RAI-MDS 2.0 is implemented in jurisdictions as a comprehensive assessment for front-line clinicians to help plan and monitor resident care; the data is then used in aggregate form to support health system use. The data submitted to CCRS is therefore a by-product of the ongoing processes of care. The assessment is captured electronically, and the vendor software the facility uses can provide real-time feedback for facility staff to support care planning. CCRS provides participating organizations with eReports, which have profiles of their populations, services and outcomes, including quality indicators. These reports are used by clinical quality champions, managers and policy-makers for planning, quality improvement and accountability. Standard tables of aggregate data are available to the public through CCRS Quick Stats.	
	Database also used by users external to Custodian	
Populations	Population groups included in this database – The CCRS captures information on individuals in publicly funded facilities of two types: 1) Hospitals that have beds designated and funded as continuing care beds, commonly known across Canada as extended, auxiliary, chronic, or complex care beds; and, 2) Residential care facilities, commonly known across Canada as nursing homes, personal care homes or long-term care facilities.	
	Population Coverage - % of population targeted by the database that has been captured: In the organizations who have adopted the CCRS, 100% of continuing care clients with stays > 14 days are covered (even for short stays, a smaller amount of information is collected, but not the RAI-MDS 2.0). CCRS is a longitudinal reporting system, and facilities are expected to submit an assessment in each quarter the resident is in the facility until he or she is discharged.	
	Alternatively, sample with weights? No. If yes, sample size	
Records	Total # of records in database: The CCRS now contains assessment data from almost 1,100 facilities in seven provinces and territories across Canada, representing information for over 520,000 unique residents. As of Q1 2011, there were more than 3, 300,000 records in the database.	Annual number of records collected/updated:
Contact/ Questions	Support Organization CIHI Title of person in support role: Natalie Damiano Name: CIHI Phone: 613-694-6492 E-mail: NDamiano@cihi.ca	
Web site	www.cihi.ca.	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question



AA4a	TREATY/BAND	☐☐☐ Band ☐☐☐☐☐ Treaty ☐☐ Placement

Note: This question is planned to be changed at a future time to: Client identifies self as First Nations (yes, no), Métis (yes, no), Inuit (yes, no).

Question Design

Reason why the above question and/or identifier were chosen: This data element was aligned with a Health Canada definition in 2002 in collaboration with interRAI. Also, different identity questions in CIHI databases were adopted at different times, and are the Canadianized version of international standards set by InterRAI, who develops and owns the assessment instruments. Starting in 2012, CIHI is moving towards a harmonization of these questions. As of 2012-2013, the data element will be updated as noted in Demographics and Ethno-cultural Identity Question sections above.

Ethno-cultural identity question(s) has been tested No
Test report re question design is available No
Name/citation for test report:

Method

This method for collecting accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Aboriginal status is collected as part of RAI-CCRS assessment, and can be used for aggregate analysis of health status, access and outcomes. As of 2012-2013, the RAI-CCRS clinical assessment will require that the clinician ask the client or family whether the client identifies him or herself as a member of an Aboriginal community (Inuit, Métis, or First Nations). The data element was originally aligned with a Health Canada definition in 2002 in collaboration with interRAI, and is being updated to reflect a more systematic approach and growing interest across the country in First Nations, Inuit and Métis identifiers. The understanding of populations is critical to providing appropriate access and service quality; it is particularly important to understand and meet the needs of vulnerable populations. There is considerable research to indicate that Aboriginal populations are at risk for particular diseases, illnesses or injuries. Both Health Canada and Statistics Canada collect information on Aboriginal origin for a variety of purposes. This CIHI data element will provide a unique perspective on Aboriginal people receiving continuing and long term care services. It will allow for the analyses of health and functional status, access to services, and health outcomes across populations that have unique health needs. It will provide real-time feedback to care providers on residents' health status and potential risks. And it will be critical in development of valid, comparable indicators, which support quality improvement initiatives.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No
Test/pilot/evaluation report is available Select One
Title/citation for report:

Data Linkage

Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1.

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

Data Quality

Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
A systematic approach to evaluating the quality of ethno-cultural identification data is in place	No
Data quality indicators that are used:	
Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Title/citation for test/pilot/quality evaluation report: Data Quality Documentation, Continuing Care Reporting System, 2008–2009
	The RAI-MDS 2.0 has undergone significant reliability and validity testing, internationally and in Canada, 2–11 which confirmed the RAI-MDS 2.0 has both high reliability and high validity. In 2007, the Ontario Ministry of Health and Long-Term Care and CIHI funded an inter-rater reliability study and secondary data quality analysis within Ontario CCC hospitals and units carried out by Canadian interRAI researchers. This comprehensive assessment instrument contains over 500 data elements documenting the clinical and functional characteristics of residents. The RAI-MDS 2.0 User's Manual provides data element definitions and data collection standards. The CCRS Specifications Manual provides information on how the data is to be submitted to CCRS and includes data element specifications, valid code values, record layouts, data validation rules and error message descriptions. Organizations participating in CCRS can access CIHI's products and services related to data quality and processing, client education and support, data access, national health information standards and select publications and reports. When clients submit data files to CCRS, data quality reports are made available to them immediately after the records are processed. CIHI checks each record on submission to ensure the record is complete and the values are valid. Any records that do not meet these specifications are rejected, and data providers are given a report detailing the reasons for the rejection. Data quality audit reports are produced 45 days after the end of a data submission quarter. They identify potentially missing records and illogical or suspicious values in successfully submitted data. Data submitters then have an additional 15 days to submit corrections and/or missing data. Through a comprehensive program of education, instructional sessions are provided to clients on using the RAI-MDS 2.0 assessment, submitting data, managing submission errors and corrections and using the CCRS information and eReports. These sessions are one mechanism to ensure standardized data collection coding practices and adherence to CIHI's data submission and collection requirements.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Comments on cost (optional)
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: Frontline staff adherence in asking all clients the Aboriginal identification question.

III. DATA ACCESS

Privacy Constraints	CIHI will receive personal information for the CCRS from provincial/territorial ministries hospitals and long term care homes on the basis of their statutory authority to disclose such data to CIHI. All provinces and territories have public sector privacy legislation in place, and four provinces also have health information acts, namely Ontario, Manitoba, Saskatchewan and Alberta. The Freedom of Information and Protection of Privacy Act in British Columbia applies to information collected for CCRS by government-funded providers. In Ontario, CIHI is a prescribed entity status under the Personal Health Information Protection Act. CIHI is an information manager for Alberta Health and Wellness and several Regional Health Authorities in Alberta under the Alberta Health Information Act. Provincial and Territorial data protection laws (for example, in Yukon) cover health care providers employed by government agencies. CIHI also collects, uses, discloses, and retains personal health information for the CCRS in accordance with: 1) Bilateral and data sharing agreements signed between CIHI and the provinces and territories in support of data collection, such as the CCRS, and any subsequent data sharing with authorized users. 2) CIHI's Privacy Policy. A full privacy impact assessment has been conducted: Continuing Care Reporting System (CCRS) Privacy Impact Assessment, 2006. The Continuing Care Reporting System Advisory Committee provides advice and direction on the policies and procedures, including quality assurance and privacy, related to the data collection, processing and dissemination of the CCRS.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:

III. DATA ACCESS

First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One | Inuit Land Claims research protocols Select One | Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: 1. Unknown to CIHI (provinces may be using the information). 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use No Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes In addition to current data submission from BC, Yukon, Saskatchewan, WRHA, ON, NL and NS, implementations are underway in Alberta Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers:

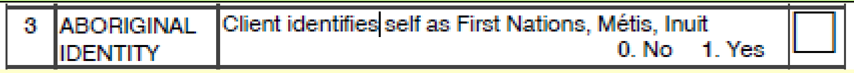
5.4.3 Home Care Reporting System

I. DATABASE – Home Care Reporting System	
Geography	☐ Canada ☒ BC ☒ AB ☒ SK ☒ MB ☒ ON ☐ QC ☐ NB ☒ NS ☐ PE ☐ NL ☒ YT ☐ NT ☐ NV ☐ Other Specify
Description	The Home Care Reporting System (HCRS) contains demographic, clinical, functional and resource utilization information on clients served by publicly funded home care programs in Canada, from jurisdictions participating in the HCRS. The HCRS captures data from various types of organizations that are responsible for providing publicly funded home care services. Data submissions to HCRS may flow from provincial or territorial ministries of health or from regional organizations (such as RHAs, CCACs or CLSCs). The HCRS captures standardized client-specific clinical, demographic, administrative and resource utilization information within a single reporting framework.
Custodian	Canadian Institute for Health Information (CIHI)
	Mandate of Custodian: Work with stakeholders to create and maintain a broad range of health databases, measurements and standards that provide essential information on Canada's health system and the health of Canadians.
Purpose	The purpose of the Home Care Reporting System is to • collect, process and analyze data on publicly funded home care services; • support management decision-making at the organizational, regional and provincial/territorial levels; • facilitate provincial/territorial and national comparative reporting; and • support related approved analysis and research.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☒ Aboriginal ☐ Other Specify
	Demographic information may be collected as part of a RAI-HC assessment or through other processes, such as referral and admission. The Home Care Reporting System is planning to move to separate identification for First Nation, Inuit and Métis in 2013
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates:
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): April 2000 Month/year of latest available ethno-cultural identifiers: 2011
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One

I. DATABASE – Home Care Reporting System

Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☒ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - The information collected through the HCRS is designed to inform decision-making by health care professionals and home care administrators, as well as system planners and policy-makers at local, regional and provincial levels.
	Database also used by users external to Custodian
Populations	Population groups included in this database – Clients who have been accepted into publicly funded home care programs across Canada.
	Population Coverage - % of population targeted by the database that has been captured: In the organizations who have adopted the Home Care Reporting System, 100% of long-term (long-term supportive or maintenance client groups) home care clients are covered.
	Alternatively, sample with weights? No. If yes, sample size % Of population
Records	Total # of records in database: As of Q1 2011, there were over 470,000 unique clients in the HCRS, from 4 provinces/territories. From these clients, there were over 5 million records in the database. Annual number of records collected/updated:
Contact/ Questions	Support Organization CIHI Title of person in support role: Natalie Damiano Name: CIHI Phone: 613-694-6492 E-mail: NDamiano@cihi.ca
Web site	at www.cihi.ca.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	 3 | ABORIGINAL IDENTITY | Client identifies self as First Nations, Métis, Inuit 0. No 1. Yes | ☐ Note: This question is planned to be changed in 2012 to: Client identifies self as First Nations (yes, no), Métis (yes, no), Inuit (yes, no).
Question Design	Reason why the above question and/or identifier were chosen: This data element was aligned with a Health Canada definition in 2002 in collaboration with interRAI. Also, different identity questions in CIHI databases were adopted at different times, and are the Canadianized version of international standards set by InterRAI, who develops and owns the assessment instruments. Starting in 2012, CIHI is moving towards a harmonization of these questions between the interRAI-based databases; this is expected to result in a change of the question on HCRS in 2013.
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE		
Method	This method for collecting accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Aboriginal status is collected as part of RAI-HC assessment, and can be used for aggregate analysis of health status, access and outcomes.. The RAI-HC clinical assessment requires that the clinician ask the client or family whether the client identifies him or herself as a member of an Aboriginal community (Inuit, Métis, or North American Indian). This data element was aligned with a Health Canada definition in 2002 in collaboration with interRAI. The understanding of populations is critical to providing appropriate access and service quality; it is particularly important to understand and meet the needs of vulnerable populations. There is considerable research to indicate that Aboriginal populations are at risk for particular diseases, illnesses or injuries. Both Health Canada and Statistics Canada collect information on Aboriginal origin for a variety of purposes. This CIHI data element will provide a unique perspective on Aboriginal people receiving home care services outside of Health Canada First Nations and Inuit Health Branch programs. It will allow for the analyses of health and functional status, access to services, and health outcomes across populations that have unique health needs. It will be critical in development of valid, comparable indicators, which support quality improvement initiatives.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated No Test/pilot/evaluation report is available Select One Title/citation for report:	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	No
	Data quality indicators that are used:	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report:	
	Through its data quality enhancement program, CIHI strives to ensure that the quality of the information in our data holdings is suited to its intended uses and that data users are provided with good information about data quality.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: Frontline staff adherence to ask all clients the Aboriginal identification questions	

III. DATA ACCESS

Privacy Constraints	CIHI will receive personal information for the HCRS from provincial/territorial ministries of health and home care organizations on the basis of their statutory authority to disclose such data to CIHI. All provinces and territories have public sector privacy legislation in place, and four provinces also have health information acts, namely Ontario, Manitoba, Saskatchewan and Alberta. The Freedom of Information and Protection of Privacy Act in British Columbia applies to information collected for HCRS by government-funded providers. In Ontario, CIHI is a prescribed entity status under the Personal Health Information Protection Act. CIHI is an information manager for Alberta Health and Wellness and several Regional Health Authorities in Alberta under the Alberta Health Information Act. Provincial and Territorial data protection laws (for example, in Yukon) cover health care providers employed by government agencies. CIHI also collects, uses, discloses, and retains personal health information for the HCRS in accordance with: 1) Bilateral and data sharing agreements signed between CIHI and the provinces and territories in support of data collection, such as the HCRS, and any subsequent data sharing with authorized users. 2) CIHI’s Privacy Policy.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional): CIHI has engaged in an intensive collaboration doing a pilot with six First Nations communities in Alberta, in collaboration with the FNIH branch at Health Canada. As part of this, all data elements in the assessment instrument were reviewed and accepted as an appropriate standard. Also, InterRAI has experience rolling out the instrument in New Zealand with the Maori, who make up ~ 15% of the population. From the InterRAI Australia and New Zealand newsletter, Issue 4, April 2010: "As part of the New Zealand interRAI National District Health Board (DHB) Implementation Project Maori stakeholders provided a cultural review of the Home Care assessment; the scope of the items and the process of assessment, particularly from the point of view of non-Maori assessors assessing Maori clients. The cultural review found that the items on the Home Care assessment are relevant for Maori. The interRAI methodology is advantageous to assessment for Maori. The focus on the response rather than the question provides freedom for the assessor to collect the data in a culturally appropriate manner. The competency of the assessor is critical to the process. A cultural framework for assessment for Maori has been identified and specific guidelines for assessing Maori clients have been provided to the Project. The guidelines are incorporated into New Zealand interRAI training competencies. Any new information learned through the experience of the national rollout will be shared with the DHBs."
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols No Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. Unknown to CIHI (provinces may be using the information). 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use No
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes HCRS implementations are currently underway in BC, Alberta, SK, and NL, in addition to data currently in HCRS from Yukon, WRHA in MB, ON and NS. Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers:

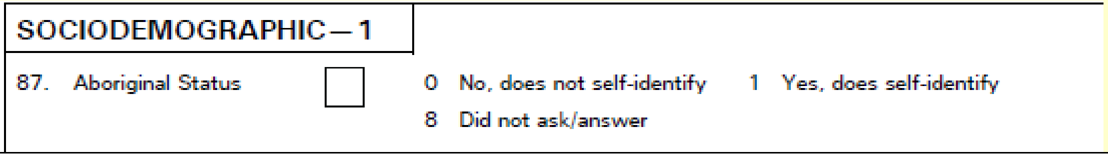
5.4.4 National Rehabilitation Reporting System

I. DATABASE – National Rehabilitation Reporting System	
Geography	☒ Canada ☒ BC ☒ AB ☒ SK ☒ MB ☒ ON ☐ QC ☒ NB ☒ NS ☒ PE ☒ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The National Rehabilitation Reporting System (NRS) records, analyzes, and reports on the level of activity and outcomes of hospital inpatient rehabilitation from approximately 101 participating facilities in nine provinces in Canada. NRS data include demographic, administrative and clinical client information.
Custodian	Canadian Institute for Health Information (CIHI)
	Mandate of Custodian: Provide pan-Canadian information on adult inpatient rehabilitation in Canada, with the goal of enhancing treatment, research and patient care.
Purpose	To provide a national view on rehab clients' characteristics, resource utilization and outcomes to support health policies, quality improvement and decisions.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☒ Aboriginal ☐ Other Specify
	NRS collects data from participating adult inpatient rehabilitation facilities and programs across Canada, including specialized facilities or hospital rehabilitation units, programs and designated rehabilitation beds. Ontario has mandated NRS data for all designated rehab beds since Oct 2002; participation in all other Provinces is voluntary. The Aboriginal status question is a mandatory data element that must be asked upon admission. Aboriginal status (Data Element 87) is a new data element included in 2009-2010 to allow CIHI to identify clients entering adult inpatient rehabilitation who identify as First Nations, Inuit Or Métis.
Status & Update	Database status Active
	Database update frequency Ongoing / on regular frequency Frequency of Updates: Facilities collect client data on admission and discharge and send the data to CIHI every quarter for inclusion in comparative reports. There is an option to collect additional info in a follow-up assessment 3-6 months after the client's rehab stay.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Apr 2009 Month/year of latest available ethno-cultural identifiers: Aug 2011
Level of Detail	1. Individual Record 2. If Individual Record was selected: Not identifiable 3. If Not identifiable was selected: Reversible
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☒ National ☒ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☒ Other Postal code of residence
	Postal Code

I. DATABASE – National Rehabilitation Reporting System

Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☒ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease	
Users	Primary users of this database - Health care facilities, clinicians, regional health authorities, ministries of health, and researchers	
	Database also used by users external to Custodian	
Populations	Population groups included in this database – Adult rehabilitation patients. The population of reference for the NRS data file is all inpatient rehabilitation episodes that occurred in participating NRS facilities in a period, and for which data was successfully submitted to the NRS.	
	Population Coverage - % of population targeted by the database that has been captured: ~100% - completion of NRS record is mandatory for all patients admitted to designated rehabilitation beds in the participating facilities in BC, Alberta, Saskatchewan, Manitoba, Ontario, New Brunswick, Nova Scotia, PEI and Newfoundland.	
	Alternatively, sample with weights? No. If yes, sample size % Of population	
Records	Total # of records in database: 327,342	Annual number of records collected/updated: approx. 38,000 episodes
Contact/ Questions	Support Organization CIHI Title of person in support role: Name: Rehabilitation Team Phone: E-mail: rehab@cihi.ca	
Web site	www.cihi.ca/nrs	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	 SOCIODEMOGRAPHIC — 1 87. Aboriginal Status ☐ 0 No, does not self-identify 1 Yes, does self-identify 8 Did not ask/answer
Question Design	Reason why the above question and/or identifier was chosen: To align with other CIHI data holdings
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report:
Method	This method for collecting accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: access, outcomes
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluate No Test/pilot/evaluation report is available No Title/citation for report:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Comprehensiveness, coverage	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes
	Title/citation for test/pilot/quality evaluation report: National Rehabilitation Reporting System, Data Quality Documentation, 2009-2010, CIHI, November 2010	
	Specifications for submitting to the NRS are available in the Rehabilitation Minimum Data Set Manual, February 2009. The new mandatory data element Aboriginal Status (data element 87) has been coded as "Does not identify with an Aboriginal community" in 98.6% of records submitted since inception of this element. As this element is mandatory, it is unknown whether this number specifically represents non-Aboriginal clients or whether it also includes Aboriginal clients who were simply not asked or refused to answer this question. This issue is especially relevant in cases in which admissions from previous years were submitted in 2009–2010. In such cases, given the now mandatory nature of this data element, there may be clients for whom this question was not asked at the time of assessment but for whom an answer is required for submission to the NRS. To mitigate this issue, the NRS introduced "Did not ask/answer" as an option for the 2010–2011 specifications. CIHI releases the NRS Data Quality Report for Provinces/Territories on an annual basis to each provincial and territorial deputy minister of health. The NRS Data Quality Report for Provinces/Territories, together with the NRS External Data Quality Report (updated annually and posted to the NRS homepage) can be used to assess and compare the quality of NRS data with a set of actionable data quality indicators.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Unknown: it is not known whether and how Canadian hospitals with inpatient rehabilitation beds currently collect ethno-cultural identifiers.	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	CIHI has in place a comprehensive and integrated privacy and security program to ensure the protection of individual privacy, confidentiality of records and security of information. A key element of CIHI's privacy and security program is CIHI's Privacy Policy, 2010, which sets out the rules on the collection, use, disclosure, retention and destruction of personal health information and de-identified data.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: No analysis by CIHI, but perhaps by the MOHs/Regions of participating facilities
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols No Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications:
	1.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions:
	1. at the participating MOHs, Regions, facilities
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use No
	Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes hospitals participating in 9 of 10 provinces
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Some consistency with other CIHI data holdings, self-identification approach Limit the re-application of this ethno-cultural identification approach to other jurisdictions: self-identification, can choose not to respond
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

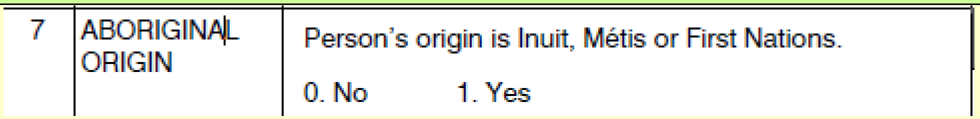
5.4.5 Ontario Mental Health Reporting System

I. DATABASE – Ontario Mental Health Reporting System				
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	The Ontario Mental Health Reporting System (OMHRS) contains data about individuals admitted to adult mental health beds in the province of Ontario. It includes information about their mental and physical health, as well as which social supports and services they use. The data is collected at admission, discharge and every three months for patients with extended stays.			
Custodian	Canadian Institute for Health Information (CIHI)			
	Mandate of Custodian: Work with stakeholders to create and maintain a broad range of health databases, measurements and standards that provide essential information on Canada’s health system and the health of Canadians.			
Purpose	OMHRS data is sourced from the Resident Assessment Instrument–Mental Health (RAI-MH)©, a unique standardized data collection system for mental health. It is used by hospitals with designated adult inpatient mental health beds as well as by specialty and provincial psychiatric hospitals. OMHRS includes data on care planning, outcome measurement, quality improvement and case mix–based funding applications. It also includes demographic, administrative and clinical information collected on clients from 74 participating hospitals in Ontario since October 1, 2005. OMHRS data helps users to explore areas such as client characteristics, resource utilization and outcomes. The RAI-MH is © Government of Ontario, Ontario Hospital Association, interRAI.			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☐ First Nation/North American Indian	☐ Inuit/Inuk	☐ Métis	☒ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☒ Other OMHRS captures Responsibility for Payment. Coding options include FNIHB
	Mandatory "Aboriginal origin" question on Admission Record; Optional on Short Stay Record.			
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates: A full admission assessment is completed on each client within 72 hours (three days) of admission to the mental health bed. This assessment includes the clinical and administrative elements of the MDS-MH, as well as demographic information, which is completed at admission only. OMHRS data is collected by clinical staff within a facility as part of the routine assessment process and entered into a vendor software application. Data is submitted to CIHI in an encrypted and secure format using the electronic Data Submission Service (eDSS) web application. Facilities receive submission reports detailing the status of the submitted files, including any rejections, via eOMHRS, available on the CIHI website. Facilities are urged to correct and resubmit rejected records. .		

I. DATABASE – Ontario Mental Health Reporting System

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): OCT-05 Month/year of latest available ethno-cultural identifiers: Sept/2011
Level of Detail	1. Individual Record 2. If Individual Record was selected: Not identifiable 3. If Not identifiable was selected: Reversible
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - The information collected through the RAI-MH is designed to inform decision-making by health care professionals and hospital administrators, as well as system planners and policy-makers at regional and provincial levels.
	Database also used by users external to Custodian
Populations	Population groups included in this database – individuals who receive services in designated adult inpatient mental health beds in general and specialty facilities in the province of Ontario. As of September 2011, 74 facilities had submitted data to CIHI for OMHRS
	Population Coverage - % of population targeted by the database that has been captured: ~100% - completion of OMHRS record is mandatory for all patients admitted to a designated adult mental health bed in Ontario
	Alternatively, sample with weights? No. If yes, sample size % Of population
Records	Total # of records in database: 559,772 16,973 (3%) of total assessments have coded BB7 (Aboriginal origin). Annual number of records collected/updated: ~100,000
Contact/ Questions	Support Organization CIHI Title of person in support role: Name: CIHI Phone: E-mail: omhrs@cihi.ca
Web site	at www.cihi.ca/omhrs.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	 7 ABORIGINAL ORIGIN Person's origin is Inuit, Métis or First Nations. 0. No 1. Yes
Question Design	Reason why the above question and/or identifier were chosen: This data element was aligned with a Health Canada definition in 2002 in collaboration with interRAI to be a standard data element on the RAI-MH.
	Ethno-cultural identity question(s) has been tested No Test report re question design is available No Name/citation for test report:

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Method	This method for collecting accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Required for aggregate analysis of health status outcomes for a vulnerable population. There is considerable research to indicate that Aboriginal populations are at risk for particular diseases, illnesses or injuries. Both Health Canada and Statistics Canada collect information on Aboriginal origin for a variety of purposes. The RAI-MH© clinical assessment requires that the clinician ask the client or family whether the client identifies him or herself as a member of an Aboriginal community (Inuit, Métis, or North American Indian). This data element was aligned with a Health Canada definition in 2002 in collaboration with interRAI. The understanding of various populations is critical to providing appropriate access and service quality; it is particularly important to understand and meet the needs of vulnerable populations. It will allow for the analyses of health and functional status, access to services, and health outcomes across populations that have unique health needs. It will be critical in development of valid, comparable indicators, which support quality improvement initiatives.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluate No Test/pilot/evaluation report is available No Title/citation for report:	
Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Comprehensiveness, coverage, etc. (cf. comments below)	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report:	
	Specifications for submitting to the OMHRS are available in the OMHRS Resource Manual. A major component of data quality occurs at the level of data capture. CIHI offers a number of support channels to participating facilities in order to promote data quality: • Documentation of coding guidelines in the Ontario Mental Health Reporting System Resource Manual; • A range of face-to-face and web-based education sessions covering assessment and coding, data collection and submission, and OMHRS outputs; • Information bulletins and newsletters covering specific topics disseminated to OMHRS clients to provide clarification around coding guidelines and to inform them of any system updates or changes; • Detailed submission reports that describe errors on rejected assessments and flag potentially suspicious data on accepted records; • Quarterly facility-level data quality reports to help facilities identify data quality issues; • An annual data quality assessment report (using the CIHI Data Quality Framework); • Ad hoc data quality analyses initiated by CIHI or by stakeholders; • Annual vendor and facility testing to ensure that the data collection software system is compliant with OMHRS submission requirements; • An annual review and enhancement of submission specifications;	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	• A web-based searchable application called eQuery for frequently asked questions; and • Client support via email, phone or teleconference on coding, data collection and submission and report interpretation. CIHI conducts two types of data quality checks on OMHRS submitted to CIHI. The first data quality check, referred to as Validation and Integrity Testing, involves identifying duplicate records, missing records, invalid data, and inconsistencies in the data, such as impossible combinations. Such records are rejected, requiring the submitting organization to revise them. Once the data successfully pass the step of Validation and Integrity Testing, the quality of the data is further analyzed to identify “potential errors,” that is, unusual combinations of data, or outliers, which may not be errors that merit further investigation. The reporting facility is responsible for investigating and, where necessary, correcting and resubmitting data. Clinical coding instructions for capture of Aboriginal Origin are included in the OMHRS Coding Manual: BB7. Aboriginal Origin Intent: To document Aboriginal status, if applicable. Definition: Aboriginal status refers to self-identification as a member of an Aboriginal community, including Inuit, Métis or First Nations. Process: Ask the person or family members, or check medical records if available. This element is based on self-identification and does not require proof (that is, a status card) to report in the positive. Coding Code “0” if the person is not a member of an Aboriginal community. Code “1” if the person is a member of an Aboriginal community.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Unknown: it is not known whether and how Ontario hospitals with mental health beds currently collect ethno-cultural identifiers.
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:

III. DATA ACCESS

Privacy Constraints	CIHI collects, uses, discloses and retains personal health information in accordance with PHIPA, CIHI’s Privacy Policy, and any agreements between CIHI and the MOHLTC, including the bilateral agreement, the PHIPA Agent Agreement, the PHIPA Prescribed Entity Agreement and the OMHRS license agreement, and any service agreements between CIHI and the submitting facilities.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: Research by third parties (ex fetal alcohol spectrum disorder, substance abuse).
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Not Applicable An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Aware via existing CIHI First Nations, Inuit, Métis strategy and other activities

III. DATA ACCESS

OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:		
	First Nations OCAP principles No	Inuit Land Claims research protocols No	Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions No Examples of evidence-informed decisions: 1. CIHI has not conducted analyses using Aboriginal Origin data 2. Perhaps the Ontario MOHLTC or interRAI has
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use No Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Newfoundland and Labrador, Manitoba are considering implementation of the RAI-MH in some of their jurisdictions. Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers: The OMHRS database is scalable, designed for pan-Canadian usage and expansion of the reporting system to other Canadian jurisdictions is expected in the coming years. For inquiries related to RAI-MH mental health reporting or education in Canada, please contact the OMHRS team at CIHI. The RAI-MH is a suite of products that includes: • The Minimum Data Set for Mental Health © (MDS-MH) with approximately 300 data elements; • 28 Mental Health Assessment Protocols © (MHAPs) for care-planning; • 32 Quality Indicators for Mental Health (QIMH), 12 Outcome Measures based on clinical scales; and • The System for Classification of In-Patient Psychiatry (SCIPP), the case-mix methodology developed for use with the MDS-MH data. 2.1 The Need for OMHRS 2.1.1 National Perspective Mental health is a federal health care priority, as reflected in the November 2002 Kirby Report and the associated Senate Committee hearings. iii The primary message to the Senate Committee was that the collection of mental health data to date is limited in that it represents only a fraction of the services provided for the treatment of mental illness. To provide and better manage mental health services, the report suggested the need for the

IV. DATA USE & REPORTING

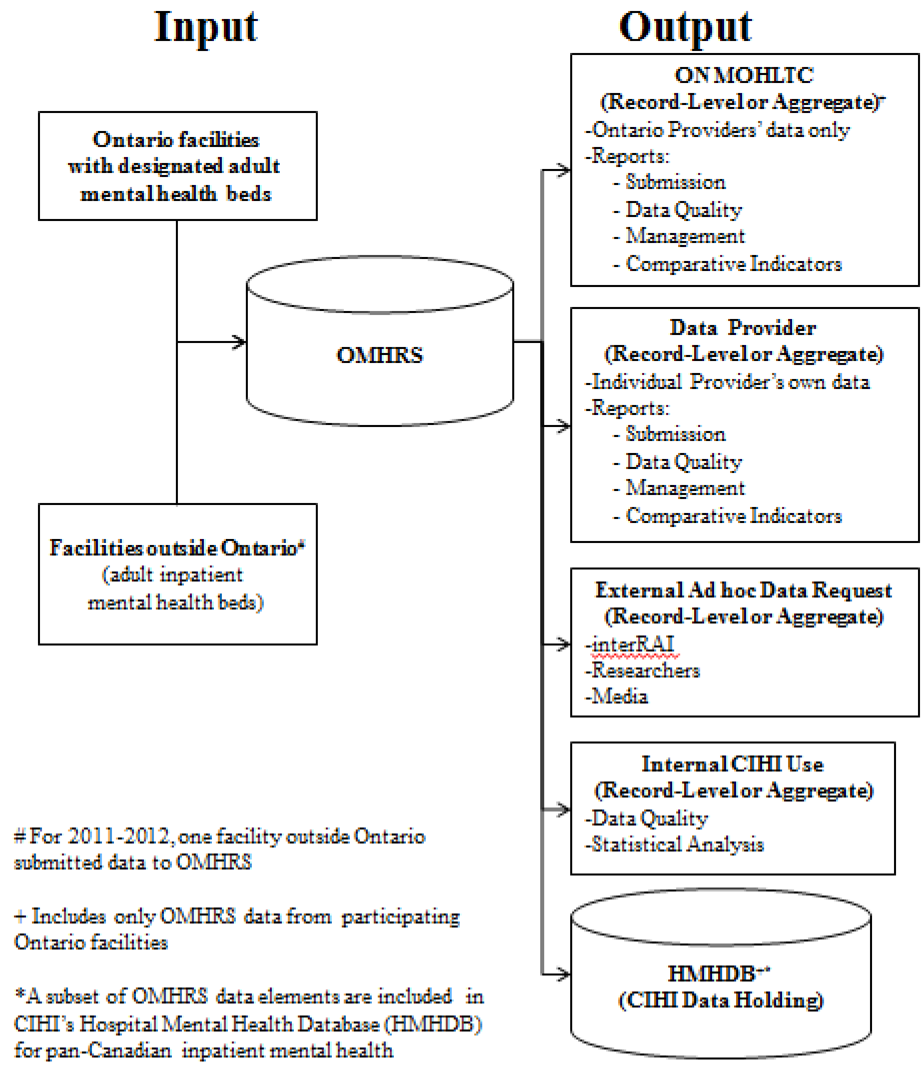
collection of additional standardized national mental health data. Implementation of OMHRS is one initiative toward addressing the acknowledged data collection gap in inpatient health services information, and the challenge of the lack of good quality and clinically relevant data at the individual level. Clinical data collection through the RAI-MH© instrument will benefit multiple stakeholder groups through its support of clinical information for care planning, quality improvement, outcome measurement, and case mix-based payment systems. iv Furthermore, OMHRS will provide information on resource allocation and performance and accountability in the inpatient population.

2.1.2 Ontario Perspective

OMHRS replaces the Discharge Abstract Database (DAD) and the Hospital Mental Health Survey as the mechanism for collecting data on adult inpatients occupying designated mental health beds in Ontario. As a result, OMHRS will also be a source of data for CIHI’s pan-Canadian Hospital Mental Health Database (HMHDB) beginning with 2006–2007 data. Since the HMHDB contains a limited data set of event-based administrative and diagnostic data, OMHRS presents an opportunity to expand the utility and breadth of inpatient mental health reporting at a longitudinal and person-based level.

Below is the data flow diagram for OMHRS

IV. DATA USE & REPORTING



For 2011-2012, one facility outside Ontario submitted data to OMHRS

+ Includes only OMHRS data from participating Ontario facilities

*A subset of OMHRS data elements are included in CIHI's Hospital Mental Health Database (HMHDB) for pan-Canadian inpatient mental health hospitalizations.

5.4.6 Primary Health Care Voluntary Reporting System

I. DATABASE – Primary Health Care Voluntary Reporting System	
Geography	☐ Canada ☒ BC ☐ AB ☐ SK ☒ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☒ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	Working with jurisdictions and Canada Health Infoway, the Canadian Institute for Health Information (CIHI) led the development and release of a common and agreed-upon primary health care (PHC) electronic medical record (EMR) content standard (CS) in early 2011. This pan-Canadian standard is increasingly being used in EMR applications to support PHC delivery and improved health system management. Beginning in FY 201-2 ON, MB and NL are including the PHC EMR CS in their EMR specifications for EMR vendors - with NS, NB and BC expected for 2012-13. Once the EMR CS is implemented, CIHI is collaborating with clinicians and jurisdictions on a subset of that data flow to the PHC Voluntary Reporting System (PHC VRS) to support health system analysis and reporting. Data collection in PHC VRS is currently from sites in ON, MB, and BC, with NS sites expected by end 2011-12.
Custodian	Canadian Institute for Health Information (CIHI)
	Mandate of Custodian: Work with stakeholders to create and maintain a broad range of health databases, measurements and standards that provide essential information on Canada's health system and the health of Canadians.
Purpose	To collaborate with key stakeholders across the country to address priority information needs in primary care. This includes data solutions (standards and data source development) as well as information solutions (indicators and service delivery analyses) that can be used to better understand this facet of care, report on priority PHC indicators and inform health policy and decision-making at various levels. Data solutions includes the pan-Canadian PHC EMR Content Standard, which is a national standard to support the data required for primary health care delivery in the community setting as well as to support data necessary for health system management. For information solutions, only a subset of the PHC EMR CS data is expected to flow to the PHC VRS (Voluntary Reporting System). For example, name address and phone number would not flow to the PHC VRS.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☒ capacity & utilization planning ☒ performance mgmt. & accountability
	☒ Research ☒ population ☒ clinical ☒ program/service ☒ public policy
	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☒ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	The new primary health care EMR standards are being implemented in FY 2011-12 in Ontario, Manitoba and Newfoundland. Data flow to the PHC VRS will be encouraged in jurisdictions that have implemented the standard. Full implementation of the PHC EMR CS is expected to occur over the next 2-3 years. Though data is currently collected in the PHC VRS from ON, MB and BC-much of the data is unstructured and data elements such as aboriginal status are not currently available.
Status & Update	Database status Active
	Database update frequency Ongoing / on regular frequency Frequency of Updates: bi-annual; moving to quarterly with EMR CS implementation

I. DATABASE – Primary Health Care Voluntary Reporting System

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): TBC Month/year of latest available ethno-cultural identifiers: Not Available until FY 2012-13 with implementation of the PHC EMR CS.
Level of Detail	1. Select One 2. If Individual Record was selected: Select One 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Specify
	Forward Sortation Area
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☒ Primary Care ☐ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Clinicians, health service administrators, policy makers and researchers-at present the data is made available to clinicians via quality feedback reports. Longer term the intent is to provide public aggregate data files and jurisdictional reporting at an aggregate level.
	Database also used by users external to Custodian
Populations	Population groups included in this database – Canadians under the care of primary care physicians-at present 300 FPs and 350,000 unique patients (longitudinal since 2009)
	Population Coverage - % of population targeted by the database that has been captured:
	Alternatively, sample with weights? No. If yes, sample size % Of population
Records	Total # of records in database: Annual number of records collected/updated:
Contact/ Questions	Support Organization CIHI Title of person in support role: Name: CIHI Phone: E-mail: phcvrs@cihi.ca
Web site	at www.cihi.ca.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

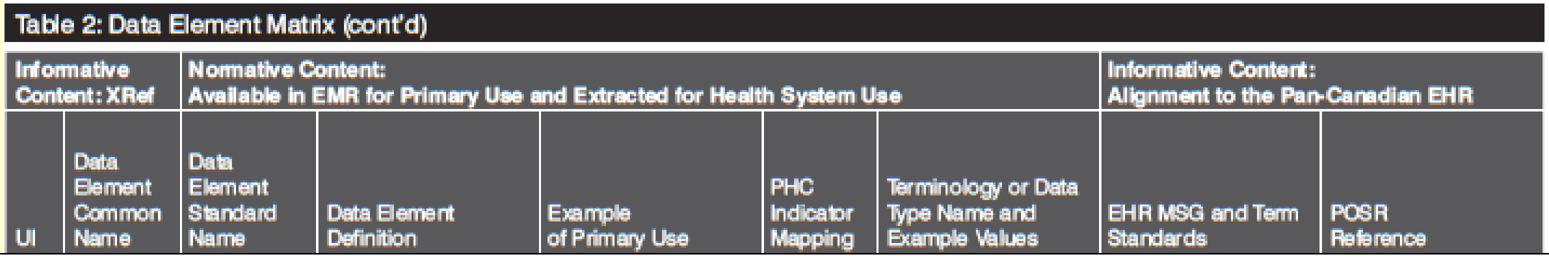


Table 2: Data Element Matrix (cont'd)

Informative Content: XRef		Normative Content: Available in EMR for Primary Use and Extracted for Health System Use					Informative Content: Alignment to the Pan-Canadian EHR	
UI	Data Element Common Name	Data Element Standard Name	Data Element Definition	Example of Primary Use	PHC Indicator Mapping	Terminology or Data Type Name and Example Values	EHR MSG and Term Standards	POSR Reference

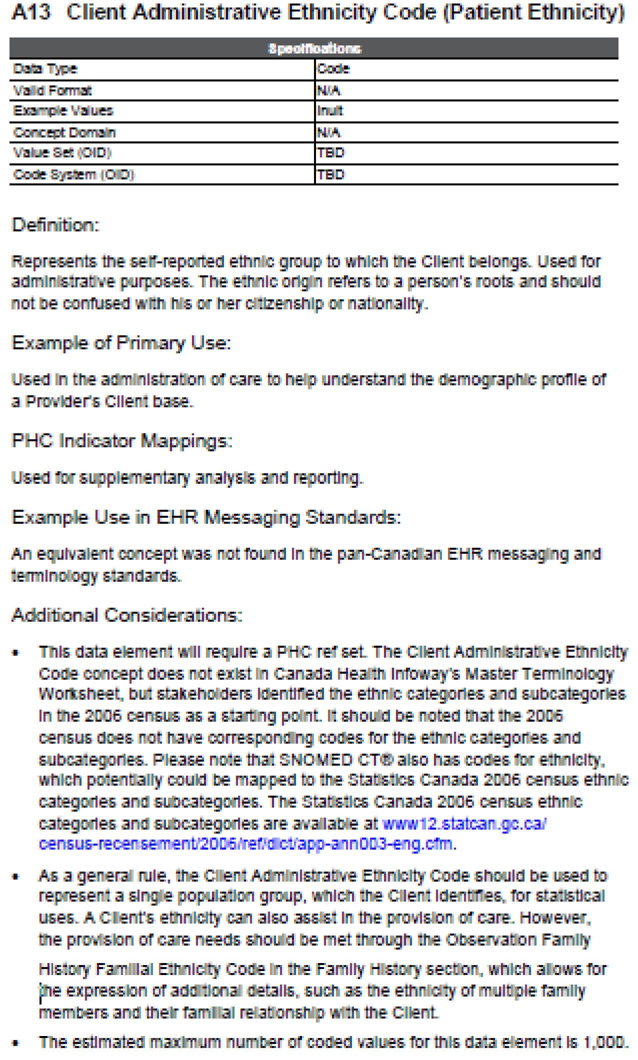
II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

A13	Patient Ethnicity	Client Administrative Ethnicity Code	Represents the Client's self-reported ethnic group to which he or she belongs, for administrative purposes. Therefore, the ethnic origin refers to a person's "roots" and should not be confused with his or her citizenship or nationality.	Used in the administration of care to help understand the demographic profile of a Provider's client base. Note: knowing a Client's ethnicity can also assist in the provision of care. However, the provision of care needs should be met through the Family History Familial Ethnicity Code in the Family History section, which allows for the expression of additional details such as the ethnicity of multiple family members and their familial relationship with the Client.	Supplementary—used for analysis and reporting	Statistics Canada 2006 Census—ethnic categories and subcategories Example: Inuit	An equivalent concept was not found in the pan-Canadian EHR Messaging and Terminology Standards.	This data element does not currently support any of the POSR records.

				may be at higher risk of developing it.				
E10	Family Member Ethnicity	Observation Family History Familial Ethnicity Code	Represents the ethnicity of the family member.	Used in the provision of care. Family History Familial Ethnicity Code is often recorded to note that the Client may have a risk factor for diseases and social behaviours. For example, some health conditions are more prominent in certain ethnic groups such as sickle cell anaemia in people with African origins.	Supplementary—used for analysis and reporting	Statistics Canada 2006 Census—ethnic categories and subcategories Example: Hispanic	An equivalent concept was not found in the pan-Canadian EHR Messaging and Terminology Standards.	Record 108, Consolidates patient history, recent test results and information displayed in a single, summary view (default view and ability to customize).

Draft Pan-Canadian PHC EMR Content Standard, Version 2.0—Business View : detailed information on the 106 data elements, including their standard names, definitions, domain values and alignment to pan-Canadian electronic health record messaging and terminology standards and physician office system requirements, pages 46 and 58.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



A13 Client Administrative Ethnicity Code (Patient Ethnicity)

Specifications	
Data Type	Code
Valid Format	N/A
Example Values	Inuit
Concept Domain	N/A
Value Set (OID)	TBD
Code System (OID)	TBD

Definition:

Represents the self-reported ethnic group to which the Client belongs. Used for administrative purposes. The ethnic origin refers to a person's roots and should not be confused with his or her citizenship or nationality.

Example of Primary Use:

Used in the administration of care to help understand the demographic profile of a Provider's Client base.

PHC Indicator Mappings:

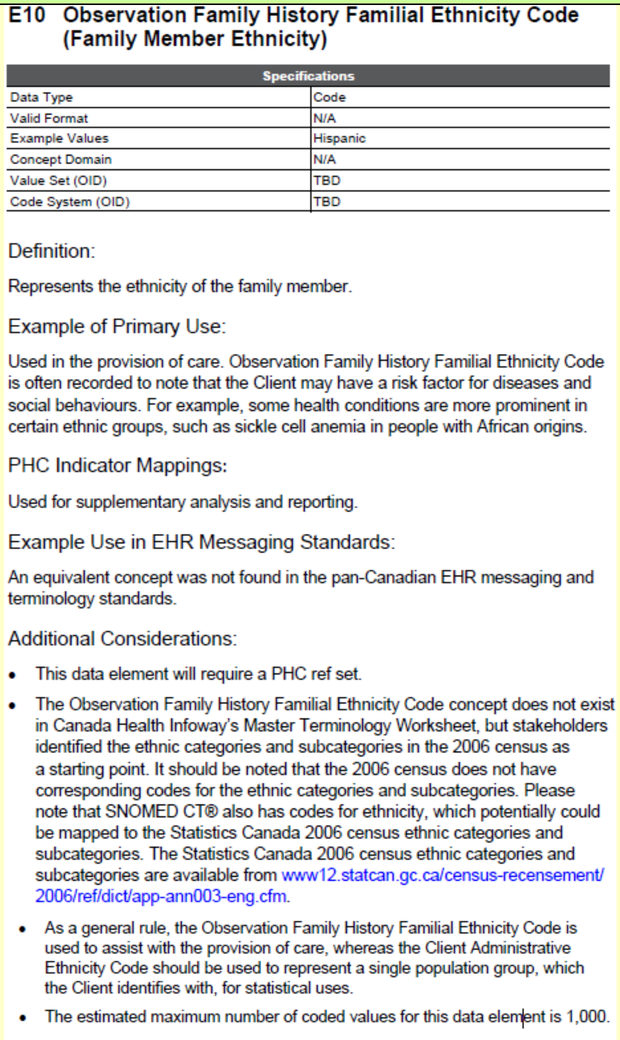
Used for supplementary analysis and reporting.

Example Use in EHR Messaging Standards:

An equivalent concept was not found in the pan-Canadian EHR messaging and terminology standards.

Additional Considerations:

- This data element will require a PHC ref set. The Client Administrative Ethnicity Code concept does not exist in Canada Health Infoway's Master Terminology Worksheet, but stakeholders identified the ethnic categories and subcategories in the 2006 census as a starting point. It should be noted that the 2006 census does not have corresponding codes for the ethnic categories and subcategories. Please note that SNOMED CT® also has codes for ethnicity, which potentially could be mapped to the Statistics Canada 2006 census ethnic categories and subcategories. The Statistics Canada 2006 census ethnic categories and subcategories are available at www12.statcan.gc.ca/census-recensement/2006/ref/dict/app-ann003-eng.cfm.
- As a general rule, the Client Administrative Ethnicity Code should be used to represent a single population group, which the Client identifies, for statistical uses. A Client's ethnicity can also assist in the provision of care. However, the provision of care needs should be met through the Observation Family History Familial Ethnicity Code in the Family History section, which allows for the expression of additional details, such as the ethnicity of multiple family members and their familial relationship with the Client.
- The estimated maximum number of coded values for this data element is 1,000.



E10 Observation Family History Familial Ethnicity Code (Family Member Ethnicity)

Specifications	
Data Type	Code
Valid Format	N/A
Example Values	Hispanic
Concept Domain	N/A
Value Set (OID)	TBD
Code System (OID)	TBD

Definition:

Represents the ethnicity of the family member.

Example of Primary Use:

Used in the provision of care. Observation Family History Familial Ethnicity Code is often recorded to note that the Client may have a risk factor for diseases and social behaviours. For example, some health conditions are more prominent in certain ethnic groups, such as sickle cell anemia in people with African origins.

PHC Indicator Mappings:

Used for supplementary analysis and reporting.

Example Use in EHR Messaging Standards:

An equivalent concept was not found in the pan-Canadian EHR messaging and terminology standards.

Additional Considerations:

- This data element will require a PHC ref set.
- The Observation Family History Familial Ethnicity Code concept does not exist in Canada Health Infoway's Master Terminology Worksheet, but stakeholders identified the ethnic categories and subcategories in the 2006 census as a starting point. It should be noted that the 2006 census does not have corresponding codes for the ethnic categories and subcategories. Please note that SNOMED CT® also has codes for ethnicity, which potentially could be mapped to the Statistics Canada 2006 census ethnic categories and subcategories. The Statistics Canada 2006 census ethnic categories and subcategories are available from www12.statcan.gc.ca/census-recensement/2006/ref/dict/app-ann003-eng.cfm.
- As a general rule, the Observation Family History Familial Ethnicity Code is used to assist with the provision of care, whereas the Client Administrative Ethnicity Code should be used to represent a single population group, which the Client identifies with, for statistical uses.
- The estimated maximum number of coded values for this data element is 1,000.

Draft Pan-Canadian Primary Health Care Electronic Medical Record Content Standard, Version 2—Implementation Guide, pages 24/ 25 and 55/56

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design	Reason why the above question and/or identifier were chosen: Stakeholders identified the ethnic categories and subcategories in the 2006 census as a starting point. For Aboriginal peoples, these are North American Indian, Inuit and Métis. The total estimated number of coding values for this data element is 1,000.	
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report: The ethno-cultural taxonomy in the census has been extensively tested and optimized. The application to PHC EMRs is being developed and its application will be largely driven by clinician behaviour.	
Method	This method for collecting accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: Knowing a client's ethnicity can assist in the provision of care. However, the provision of care needs should be met through the Family History Familial Ethnicity Code in the Family History section, which allows for the expression of additional details such as the ethnicity of multiple family members and their familial relationship with the Client.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluate Select One Test/pilot/evaluation report is available Select One Title/citation for report:	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used:	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Select One Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS	
Privacy Constraints	The data elements that form the core of the PHC EMR CS can be thought of as a data dictionary that defines the data elements regardless of precisely how they are implemented. As a result, the data elements may support both primary and health system uses of PHC EMR data within the same implementation. For example, the data elements can be implemented in an EMR to help drive decision-support algorithms, or they can help inform the core content of a PHC EMR data extract specification that focuses on health system uses of EMR data. Each implementation will require further specification of the use of the data elements and will need to apply additional constraints and information that support the specific implementation. For example, different implementations will need to define the conditions under which certain data elements are mandatory or optional and how and when to de-identify data. Users of the PHC EMR Content Standard, Version 2.0, including the Data Extract Specification and the Implementation Guide, should comply with the 10 privacy principles established in the Canadian Standard Association's Model Code for the Protection of Personal Information, as well as the relevant jurisdictional privacy legislation and guidance provided by privacy oversight bodies.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: Clinician provider feedback reports
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Not Applicable An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	The PHC EMR CS was developed with engagement from jurisdictions who consulted with stakeholders within their respective regions to confirm priority data elements for primary care delivery and health system use.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database No Examples of analyses, reports, publications: 1. Not applicable until the data collection is possible (post implementation of the PHC EMR CS). 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Preliminary consultation with Association of Ontario Health Centres (AOHC) and aboriginal clinics regarding participation in the PHC VRS.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Until PHC EMR Content Standards are implemented in the EMR applications, clinicians are not able to capture data - including ethno-cultural data - in a structured way. And upon implementation of content standards, it is still expected that a fair bit of education/ clinician training would happen to improve data capture of priority data elements.
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers: The Value “Data standards allow comparisons between patients within the practice, as well as comparisons across practices, and facilitate surveillance and a population health approach to primary health care.” Dr. Alan Katz, Family Physician, Family Medical Centre, St. Boniface General Hospital, Winnipeg, Manitoba. The collection of ethnicity data requires the implementation of the PHC EMR CS and clinician use of the data fields where warranted to capture the information. The PHC VRS is being designed as a receiver data holding where the PHC EMR CS is implemented in vendor products and will capture the ethnicity data elements where it is recorded in the PHC EMR. Within the PHC VRS, these would then be included with other information, such as: health concerns, diagnostic imaging, labs, medications, social behaviour (risk factors), referral and intervention, and date of birth; all of these can help identify vulnerable populations and support quality improvement. Please see additional information on the PHC VRS data collected.

5.0 Health Databases – National

5.5 HEALTH CANADA – FIRST NATIONS AND INUIT HEALTH BRANCH

5.5.1 Status Verification System

I. DATABASE – Status Verification System	
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The Status Verification System (SVS) is a national database that is used to store, process, track and maintain a record of every person who is eligible to receive NIHB benefits. SVS contains a complete list of registered First Nations and recognized Inuit. The Status Verification System is used within the Non-Insured Health Benefits (NIHB) Program to confirm eligibility. The information for First Nations is collected by AANDC and provided to Health Canada First Nations and Inuit Health Branch through an MOU for use by Non-Insured Health Benefits (NIHB). The information for Inuit clients is based on information provided by the Governments of the Northwest Territories and Nunavut, and Inuit organizations with responsibility for administering land claims beneficiary lists (Inuvialuit Regional Corporation, Nunavut Tunngavik Incorporated, Makivik Corporation).
Custodian	Non-Insured Health Benefits Directorate, First Nations and Inuit Health Branch, Health Canada
	Mandate of Custodian: To support First Nations and Inuit in reaching an overall health status that is comparable with other Canadians, the NIHB Program covers a specified range of medically necessary benefits. These include: • Pharmacy benefits (including prescription and over-the-counter drugs as well as medical supplies and equipment); • Dental services; • Transportation to access medically necessary services; • Eye and vision care services; • Health care premiums in British Columbia; and • Other health care services including short-term crisis intervention mental health counselling.
Purpose	Administration of a specified range of medically necessary benefits
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☒ Operating a Health Organization or System ☐ funding & reimbursement ☒ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☒ Service Delivery ☒ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☒ Band name or number
	☒ Inuit/Inuk ☒ Inuvialuit ☒ Nunavut ☒ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	The Status Verification System Is solely recognised First Nations and Inuit; it is an Active Database that is updated daily. Key Data Elements are: Name, Date Of Birth, Gender, Band, Eligibility, Status Number (for First Nations) or N-Number (for Inuit), NWT & NV Health Card Number, and Region. The System does not have address/residency information as the original processes that were set up did not require it.

I. DATABASE – Status Verification System

Data Sources	1. Indian Register, Aboriginal and Northern Affairs Canada (AANDC) - for list of registered Indians; 2. Government of the Northwest Territories - for land claims beneficiary list from Inuvialuit Regional Corporation); 3. Government of Nunavut - for land claims beneficiary list from Nunavut Tunngavik Incorporated; 4. Regional FNIHB office in Quebec - for land claims beneficiary list from Makivik Corporation.
	I. Nunatsiavut is a full transfer territory, i.e. it has complete self-government and manages its own health benefits, including pharmacy, dental etc. benefits. Hence, Nunatsiavut beneficiaries (~ 6,500) are not part of the SVS. II. For Nunavik (Makivik Corporation), only beneficiaries outside of the land claims area can qualify for the NIHB program, and hence could be part of the SVS. This is a relatively small % (< 5%) of all Makivik beneficiaries (all Makivik beneficiaries' number ~ 11,400 as of 3/31/2010). For the majority of Nunavik beneficiaries (17 Inuit communities and the James Bay Cree) who live inside the land claims area, health services are administered under the James Bay land claims agreement; in the case of the Inuit beneficiaries, Makivik Corporation administers the benefits. III. For Nunavut and Inuvialuit beneficiaries, the Territorial Governments of Nunavut and NWT help coordinate administration of NIHB benefits, regardless of whether beneficiaries live in- or outside the land claims areas.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Month/year of latest available ethno-cultural identifiers:
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Band Level for most First Nations and Regional level for Inuit
	Select One
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☒ Drugs ☐ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - NIHB Regional and HQ Users use this database to determine eligibility for program benefits
	Database also used by users external to Custodian
Populations	Population groups included in this database – Registered First Nations and Recognised Inuit residing in Canada who may be eligible for program benefits
Records	Total number of records in database: 863,361 Eligible First Nations & Inuit as of (09/19/2011). ~ 16,000 records are collected/updated each year.
Contact/Questions	Support Organization NIHB Title of person in support role: Director of OSSD Name: Douglas Booker Phone: 613-957-3294 E-mail: douglas.booker@hc-sc.gc.ca
Web site	http://www.hc-sc.gc.ca/fniah-spnia/index-eng.php. HC Web based only available to HC employees

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: No. If yes, barriers/gaps that have been addressed: No, since the information is collected and already stored by AANDC and the Inuit Land Claims Corporations; the SVS has a specific purpose in supporting the administration of the NIHB program, and is not used for record linkage or other secondary purposes.
Data Quality	All our clients are First Nation or Inuit and we must follow all Government of Canada privacy standards and Health Canada Guidelines
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One

III. DATA ACCESS

Privacy Constraints	The NIHB Program recognizes an individual's right to privacy and is committed to protecting this right and to safeguarding the personal information in its possession. When a request for benefits is received, the NIHB Program collects, uses, discloses and retains an individual's personal information according to the applicable privacy legislation. As a Program of the federal government, NIHB must comply with the Privacy Act, the Charter of Rights and Freedoms, the Access to Information Act, as well as Treasury Board of Canada privacy and data protection policies including the Privacy Impact Assessment (PIA) Policy. The latter requires all federal government programs to conduct PIAs on their processes, services and systems involved with the collection, use, disclosure and retention of personal information in order to identify any privacy-related risks and to mitigate or eliminate them. During 2009/10, NIHB updated its PIA on the Health Information and Claims Processing Services System (HICPS) in preparation for submission to the Office of the Privacy Commissioner of Canada. Consistent with its ongoing commitment to privacy, NIHB will undertake PIAs on its other systems and processes as appropriate.
	A Privacy Impact Assessment has been done for this database Yes
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Not Applicable An MOU or formal agreement governing development and/or use of the database is in place Yes First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	An MOU is in place with the Indian Register for use by the NIHB program.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No Inuit Land Claims research protocols No Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. NIHB Annual Report - SVS Information is used within Health Canada 2. Inuit Specific Technical Report is also produced annually
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions No Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes We share our Annual Report with all Bands and Inuit Organizations
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification No Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	SVS supports the delivery and payment of NIHB benefits available to eligible clients through the following systems: HICPS (Health Information and Claims Processing Services), MTRS (Medical Transportation Record System) and Regional systems such as for Vision and Mental Health. SVS was not built to provide a statistical database; its main functionality is to determine eligibility.

5.0 Health Databases – National

5.6 HEALTH CANADA – PUBLIC HEALTH AGENCY OF CANADA

5.6.1 Canadian Chronic Disease Surveillance System

I. DATABASE – Canadian Chronic Disease Surveillance System (CCDSS)				
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NV ☐ Other Specify			
Description	The Canadian Chronic Disease Surveillance System (CCDSS), formerly known as the National Diabetes Surveillance System is a collaborative network of provincial and territorial chronic disease surveillance systems, supported by the Public Health Agency of Canada. It was created to improve the breadth of information about the burden of chronic diseases in Canada so that policy-makers, researchers, health practitioners, and the general public could make better public and personal health decisions. The CCDSS uses data from various population-based sources in order to estimate the prevalence, incidence, mortality, and the utilization of health care services related to diabetes and other chronic diseases.			
Custodian	Each participating jurisdiction holds its own database(s). The Governance Structure The Expert Group on Chronic Disease and Injury Prevention and Control of the Public Health Network is the accountable body for the CCDSS. It decides what conditions will be added to the system; reviews the CCDSS work plans; and monitors the CCDSS implementation and its impact. The Task Group on Surveillance of Chronic Disease and Injury, with representatives from all provinces and territories, provides advice to the Expert Group on these functions. It will also be responsible for the technical and science decisions including case definitions, analytic plans, and the interpretation of the data. The CCDSS Technical Working Group implements, improves and enhances the software and technical documentation for capturing the surveillance information. The persons involved with the technical operation of the CCDSS from all provinces and territories are members of this group in addition to the Operations team at the Chronic Disease Surveillance Division.			
	Mandate of Custodian: Not applicable (different for each custodian)			
Purpose	The CCDSS provides a national, standardized database of Canadian data on several chronic disease including diabetes, hypertension, chronic respiratory disease (Asthma, COPD) , Mental Illnesses and other diseases (as feasibility is confirmed) and their complications. This source of data will provide a foundation for effective planning and evaluation of chronic disease prevention or control programs.			
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other chronic diseases	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy	☒ Service Delivery ☐ enrolment/membership ☒ evaluation ☐ equity ☐ patient navigation

I. DATABASE – Canadian Chronic Disease Surveillance System (CCDSS)

Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☐ Inuit/Inuk	☐ Métis	☐ Aboriginal
	☒ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
	The prevalence of diabetes among some First Nations populations is three to five times the national rate. Rates are even higher among some First Nations language groups and there is a North-South gradient, with people in the south having higher diabetes rates than those in isolated northern communities. NDDS contains an "Aboriginal Component" intended to address some of the unique information concerns of these populations. A goal of the NDDS has been to encourage and facilitate the collaboration between the Aboriginal peoples and the provinces and territories so that, together, we can better understand and track the severity of diabetes in these communities. In British Columbia there has been a successful example of this approach. A partnership was formed between the British Columbia Ministry of Health, Indian and Northern Affairs (INAC), Health Canada and the First Nations Leadership Council. As a result, data representing about 168,000 First Nations people who lived in British Columbia and were included in either the Status Verification File (SVF) or the British Columbia Medical Services Plan Entitlement File were analysed. The results were presented in the "Provincial Health Officer's Annual Report 2007". This group represents about 4% of the total British Columbia population.			
Data Sources	1. Provincial/territorial physician claims/ physician billing databases; 2. CIHI Discharge Abstract Database (DAD) - administrative hospital records; 3. Provincial/ territorial insurance coverage files/ patient registries. Person-level data will remain with each Province and Territory, and data on population groups (i.e., aggregated data) will be sent to Public Health Agency for analysis and national comparison. Standardized methods are used to determine prevalence, incidence, mortality and health services utilization of several chronic diseases across Provinces and Territories.			
	In each province and territory, the health insurance registry database is linked to the physician billing and hospitalization databases. This surveillance system summarizes data about residents of Canada who have used the Canadian health care system. If there is sufficient evidence of use due to the selected chronic diseases it was assumed that a person had diagnosed with the selected chronic diseases. For example, for diabetes, the minimum requirement is at least 1 hospitalization or 2 physician claims, with a diabetes specific code(s), over a 2-year period. The CCDSS Diabetes case criteria were designed to exclude women with gestational diabetes, because it typically resolves after delivery.			
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98):	Month/year of latest available ethno-cultural identifiers:		
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☒ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Specify			
	Select One			

I. DATABASE – Canadian Chronic Disease Surveillance System (CCDSS)

Service Domain	☒ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☒ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☒ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - Policymakers, researchers, health practitioners, and the general public . Database also used by users external to Custodian
Populations	Population groups included in this database – Canadians with type 1 or type 2 diabetes, hypertension, chronic respiratory diseases (asthma, COPD), some mental illnesses: mood & anxiety disorder, omnibus mental illness. The database is also actively working towards incorporating muskulo-skeletal and cardio-vascular disorders (AMI, stroke, heart failure) in the near future.
Records	Total number of records in database: ~ 33 million records (the full Canadian population on health insurance registries; this is a population-based database.)
Contact/ Questions	Support Organization Public Health Agency of Canada Title of person in support role: Manager, Data Management and Analysis Name: Glenn Robbins Phone: 613-946-4837 E-mail: glenn.robbins@phac-aspc.gc.ca
Web site	http://www.phac-aspc.gc.ca/ccdpc-cpcmc/ndss-snsd/english/ndss_description/index-eng.php

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: See comments below
Data Quality	Re quality of ethno-cultural data: although some provinces purport to capture some ethno cultural indicators within their Health Insurance Registry, many Aboriginal groups have indicated concerns about the quality and accuracy of those data. Many provinces and territories do not have such indicators. The PHAC has tried to facilitate the collaboration between the P/T governmental organizations responsible for implementing the CCDSS and local regional aboriginal groups. In some domains the use of the INAC file for verification of status has been used (such as British Colombia) and in others the PHAC has funded the development of membership lists by some Métis groups that could be included within the CCDSS infrastructure. The implementation of these efforts is not universal across the country yet. For example, both BC and Newfoundland have made significant progress producing reports in collaboration with the Aboriginal groups (see also Data Products below). The CCDSS has strongly encouraged the direct involvement of the various Aboriginal groups with the P/Ts and recognizes that this is more than just a technical exercise. PHAC encourages its P/T partners to work within the ideals of the OCAP to try to develop a sustainable long term relationship with the various Aboriginal groups within its boundaries. Re quality of chronic disease data: for diabetes, validation studies have indicated that the case criteria minimizes both false-negatives and false-positives in order to depict a relatively accurate picture of diagnosed diabetes in Canada. The database does miss the people who have diabetes but have not yet been diagnosed with the condition. Recent changes to the coding procedures for hospitalization data may benefit the system in the future. For example, in the latest version of the International Classification of Disease (ICD) coding system (ICD-10-CA) used by hospitals to record the details of hospitalizations, separate codes for type 1 and type 2 diabetes are provided. It is anticipated that as ICD-10-CA coded hospital data are accumulated and validated, it will be

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

	possible to analyze and report rates associated with hospitalization stratified by diabetes type. Also, beginning with the 2006-07 data, the Canadian Coding Standards for ICD-10-CA and CCI, 20097 mandated that all provinces and territories include any information about patients with diabetes in their hospitalization data. This new practice could enable the CCDSS to identify more people with diabetes, and find them earlier, from the hospitalization data. This situation will be monitored to determine the effect and magnitude on the data collected by the surveillance system.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes The CCDSS is a cost effective approach of utilizing existing provincial and territorial administrative data sources. The clinical path of diabetes (and other chronic disease) detection and treatment makes them particularly amenable for tracking through interactions with the provincial and territorial health care systems. The CCDSS involves linking these existing databases to develop longitudinal clinical histories of individual cases. Data provided to the Public Health Agency of Canada by the provinces and territories are in an aggregate form.

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database: At the national level, only aggregate data are used. At the provincial/ territorial levels, PIAs have been conducted.
	A Privacy Impact Assessment has been done for this database Yes
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Yes First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	CCDSS has endorsed the need to have Aboriginal people involved in development.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1 Population Health Surveillance and Epidemiology, Ministry of Healthy Living and Sport, 2008. Pathways to Health and Healing - 2nd Report on the Health and Well-being of Aboriginal People in British Columbia URL: http://www.hls.gov.bc.ca/pho/annual.html 2. Report from the National Diabetes Surveillance System:Diabetes in Canada, 2009, Chronic Disease Surveillance Division Centre for Chronic Disease Prevention and Control, Health Canada. 3. Miawpukek Diabetes Study Dataset: This is a composite dataset developed through the linkage of data extracted from CCDSS and chart review data carried out at Conne River Health and Social Services. The purpose of the dataset was to examine diabetes, co-morbidities, and health service utilization among the Miawpukek First Nation living on reserve in Newfoundland and Labrador. The Centre for Health Information in Newfoundland and Labrador is the custodian of this dataset.

IV. DATA USE & REPORTING

Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Diabetes studies specific to First Nations in BC and NL are examples of collaborative development and use of the data.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One The CCDSS provides a valuable source of information about diabetes and other selected chronic diseases in Canada. Future work will include: Continuing work with First Nations, Métis, and Inuit organizations to produce additional CCDSS data for analysis, interpretation, and up-to-date reporting, to gain a better understanding of diabetes among these population and continuing to foster a standard approach for high data quality.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: The experiences in British Columbia and Newfoundland, among others, appear to indicate that relationship building, role definition, setting common priorities, and capacity building go hand in hand in re-applying the approach to other First Nations, Inuit, and Métis communities. This, in turn, requires close work between community representatives, provincial and national governance and health care contributors. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Possible barriers are a) reluctance at some provincial/ territorial and community levels to share/link data sets that link health data to First Nations, Inuit and/or Métis identifiers, and b) constraints on First Nations, Inuit and Métis capacity to manage such projects, and analyse and use the resulting data. While these barriers are real, experience shows that a determined investment in the factors described under "Support" can overcome these barriers over time.
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

5.6.2 Canadian Tuberculosis Reporting System

I. DATABASE – Canadian Tuberculosis Reporting System	
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NV ☐ Other Specify
Description	The Canadian Tuberculosis Reporting System (CTBRS) is derived from records of provincial/territorial tuberculosis registries which capture information on all new active and re-treatment cases of tuberculosis and on the treatment outcomes for these cases. All provinces/territories voluntarily submit their case and outcome data to TBPC. Case data for four of the thirteen provinces/territories (Alberta, Ontario, Quebec and Saskatchewan) are submitted electronically. The remaining provinces/territories submit paper reporting forms. Outcome data are submitted electronically from Alberta, Saskatchewan, Quebec and Ontario. The remaining provinces submit outcome results on paper forms.
Custodian	HIV/AIDS and TB Core Surveillance, Surveillance and Epidemiology Division, Public Health Agency of Canada Mandate of Custodian: To promote and protect the health of Canadians through leadership, partnership, innovation and action in public health.
Purpose	To monitor trends in TB disease across Canada which provides direction in policy and planning for prevention and control activities. ☒ Public Health & Surveillance ☐ screening ☐ immunization ☒ communicable disease ☐ other Specify ☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability ☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy ☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data ☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers ☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☐ Band name or number ☒ Inuit/Inuk ☐ Inuvialuit ☒ Nunavut ☐ Nunavik ☐ Nunatsiavut ☒ Métis ☐ On Métis register ☐ Other Specify ☒ Aboriginal ☒ Other Category "Other Aboriginal (specify)" refers to persons who are not Status Indian, Métis or Inuit, e.g. non-status Indian. Definitions of ethno-cultural groups are taken from the Canadian Tuberculosis Standards, V 6: http://www.phac-aspc.gc.ca/tbpc-latb/pubs/tbstand07-eng.php.
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: annual
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Month/year of latest available ethno-cultural identifiers:
Level of Detail	1. Individual Record 2. If Individual Record was selected: Select One 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Specify Select One

I. DATABASE – Canadian Tuberculosis Reporting System

Service Domain

☐ Acute Care
☐ Palliative Care
☐ Cancer
☐ Emergency Care
☐ Long Term Care
☐ Diabetes
☐ Complex Continuing Care
☐ Home & Community Care
☐ Renal Dialysis
☐ Rehabilitation
☐ Primary Care
☐ Immunization
☐ Mental Health/Addictions
☐ Drugs
☒ Communicable Disease

Users

Primary users of this database - 1) Public health departments at local/regional, provincial/territorial and the federal level; 2) policy makers, the public, health care community and other key stakeholders, e.g. Aboriginal governance and health committees.

Select One

Populations

Population groups included in this database – Patients diagnosed with new and relapsed cases of tuberculosis.

Population Coverage - % of population targeted by the database that has been captured: It is estimated that CTBRS captures close to 100% of all incident tuberculosis cases.
From "tuberculosis in Canada 2007", available at: http://www.publichealth.gc.ca/tuberculosis: Rates are expressed as the number of cases reported each calendar year per 100,000 population. The denominators used to calculate rates for total Canadian, provincial/territorial, total Canadian-born Aboriginal, Inuit and Métis were derived from official and custom census products from Statistics Canada, Demography Division. (Statistics Canada, Demography Division, Demographic, Estimates Section, Population estimates 0-90+, July, Canada – Provinces/Territories 1971-2005, updated February, 2008.).

The rates presented for the total Aboriginal population including Métis, Inuit and North American Indian (combining Status (registered) Indian and non-Status Indian counts) were derived from the 2001 Census data published in the Projections of the Aboriginal populations, Canada, provinces and territories, 2001 to 2017. (Projections of the Aboriginal populations, Canada, provinces and territories 2001 to 2017 Demography Division,
Statistics Canada Catalogue No. 91-547-XIE.).

Current and historical incidence rates for the Status (registered) Indian population are based on population estimates from Indian and Northern Affairs Canada. These estimates are considered a more accurate reflection of the true counts of the Status Indian population. (INAC, Registered Indian Population by Sex and Residence 2005. Available at: http://www.ainc-inac.gc.ca/pr/sts/rip/rip05_e.pdf). However, using different sources does introduce possibility of conflicting numbers. As a result, caution should be observed when drawing comparative conclusions between the Status (registered) Indian and other origin groups.

Prior to 2003, in the annual Tuberculosis In Canada reports, the case counts for the Métis and non-Status Indians were combined into one aggregated number and because populations counts were not available, incidence rates were not calculated. In 2003 population estimates for the Métis were produced by Statistics Canada, Demography Division, enabling the reporting of rates for this population. Starting in 2003, case counts for the Métis were separated from those for non-Status counts and rates for the Métis were reported – accurate population counts for the non-Status Indian are not available and so incidence rates are not able to be calculated. Some jurisdictions have not been able to distinguish non-Status from the Métis cases due to constraints with their TB program's reporting system. National rates for the Métis may be over inflated and need to be interpreted cautiously. It is hoped that in working with the jurisdictions these data will become more accurate in future reports.

Alternatively, sample with weights? No. If yes, sample size % of population

Records

Total # of records in database: Approximately 96,000. Data in the CTBRS goes back to 1970.

Annual number of records collected/updated: Approximately 1600 cases annually for all of Canada.

Contact/ Questions

Support Organization Surveillance and Epidemiology Division, Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada
Title of person in support role: Epidemiologist Name: Victor Gallant Phone: 613-960-9077 E-mail: victor.gallant@phac-aspc.gc.ca

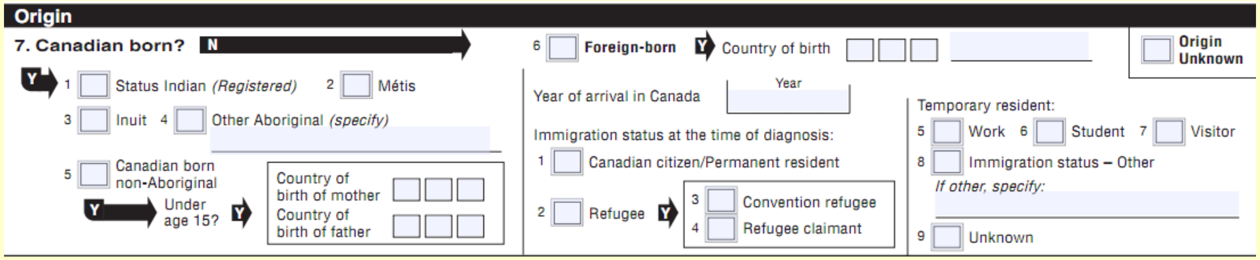
I. DATABASE – Canadian Tuberculosis Reporting System

Web site http://www.phac-aspc.gc.ca/tbpc-latb/index-eng.php

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question

Verbatim reproduction of the ethno-cultural identity question(s):



Origin

7. Canadian born? N → 6 ☐ **Foreign-born** Y → Country of birth ☐☐☐

☐ **Origin Unknown**

Y → 1 ☐ Status Indian *(Registered)* 2 ☐ Métis

3 ☐ Inuit 4 ☐ Other Aboriginal *(specify)*

5 ☐ Canadian born non-Aboriginal

Y → Under age 15? Y → Country of birth of mother ☐☐☐ Country of birth of father ☐☐☐

Year of arrival in Canada Year

Immigration status at the time of diagnosis:

1 ☐ Canadian citizen/Permanent resident

2 ☐ Refugee Y → 3 ☐ Convention refugee 4 ☐ Refugee claimant

Temporary resident:

5 ☐ Work 6 ☐ Student 7 ☐ Visitor

8 ☐ Immigration status – Other

If other, specify:

9 ☐ Unknown

Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached

Question Design

Reason why the above question and/or identifier was chosen: National definitions based on Statistics Canada Census definitions. This standard for the national Case Report Form is set by the provinces/ territories, and defines the data elements that get submitted to CTRS by the provinces/ territories, who in turn work with local/regional public health units of specific jurisdictional requirements re who is required to make a report, to whom a report is made and the specific data elements that must be reported. These typically include: demographics, risk factors for infection and disease, the sites and staging of disease, method of diagnosis, including results of lab tests, treatment regimen and outcome of treatment.

Ethno-cultural identity question(s) has been tested Select One
Test report re question design is available Select One
Name/citation for test report:

Method

This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: While the rates of TB have been declining and the overall numbers are proportionately low (1,623 cases per year over the past 7 years up to 2009), TB is increasingly a disease of high-risk populations such as Aboriginal Canadians. It is therefore important to have a process and infrastructure that allows communities - both Aboriginal and non-Aboriginal - to assess the burden of TB and the outcomes of the TB control program. During the prolonged period of treatment, treating physicians and public health staff educate patients and their family or household members about TB treatment and help reduce barriers to healing, e.g. by navigating to appropriate socio-cultural supports.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One
Test /pilot/ evaluation report is available Select One
Title/ citation for report:

Data Linkage

<u>Potential</u>, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Select One

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	No
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	No
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	No
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	No
	Title/citation for test/pilot/quality evaluation report:	
	Before the analysis and publication, all data are reviewed for errors, inconsistencies and incomplete reporting. Follow-up is done with the reporting jurisdictions identifying any concerns or problems with the reported data. Previously reported data are also subject to revision in the event of late reporting or when revised information from the provinces/ territories is received. Revisions are disseminated in subsequent reports. In general, the majority of data elements for case and outcome reports submitted to TBPC are complete. Reporting is less complete for some of the data elements introduced in 1997 such as HIV status.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Not applicable	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers:	

III. DATA ACCESS

Privacy Constraints	Confidentiality of the data is maintained as required by municipal, provincial/ territorial and federal privacy protection legislation. To avoid any potential issues with confidentiality and privacy, tables where population counts become too small may be collapsed in regions (e.g. for the three territories into “North”). In general, data will be suppressed in all instances where population denominators fall below 40.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Not Applicable An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One | Inuit Land Claims research protocols Select One | Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Tuberculosis in Canada annual reports; see http://www.phac-aspc.gc.ca/tbpc-latb/surv-eng.php. 2. Special Report of the Canadian Tuberculosis Committee: Tuberculosis among the Aboriginal peoples of Canada, 2000 to 2004; Tuberculosis Prevention and Control, Public Health Agency of Canada and First Nations and Inuit Health Branch, Health Canada 3. Tuberculosis in Canadian-born Aboriginal peoples, 1999 These are in addition to local and provincial/ territorial analyses and reports for the general population as well as Aboriginal groups.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Complete, accurate and timely data are only one part of an effective organized TB control program. Other vital elements include: 1) dedicated and trained public health staff attuned to the local epidemiology of TB and the specific needs of the community, 2) a defined mechanism for communication and coordination with local primary care and community social support providers, and 3) relationships that help ensure prompt and complete reporting, effective case management and contact tracing, more effective outreach to high-risk groups, and provision of culturally appropriate services. See also: Canadian Tuberculosis Standards, 6th Edition, 2007, Cat. N° HP40-18/2007E-PDF, ISBN 978-0-662-45956-9

5.0 Health Databases – National

5.7 STATISTICS CANADA

5.7.1 Aboriginal Peoples Survey

I.	**DATABASE – Aboriginal Peoples Survey**
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YK ☐ NT ☐ NV ☐ Other Specify
Description	There are gaps in the data that exist for Aboriginal people and the Aboriginal Peoples Survey (APS) was designed to address some of these gaps. The survey yields information that cannot be found anywhere else and can be used to answer a wide range of questions related to community planning, program development and health care priorities, among others. Over 45,000 First Nation, Inuit and Métis people participated in the 2006 survey. The APS is a cross-sectional post-censal survey that has been carried out three times, following the collection of the 1991, 2001 and 2006 Census of Population. People who report Aboriginal ancestry and/or identity on the long form census are eligible to participate in the APS. It describes the socio-economic and health status of Aboriginal peoples who live, as of the 2006 APS, mostly outside First Nations communities. The use of the census as a sampling frame enables the inclusion of some typically under-represented Aboriginal groups, such as urban Aboriginal people, Non-Status First Nations, off-reserve First Nations, and Métis.
Custodian	Statistics Canada Mandate of Custodian: To collect, compile, analyse, abstract and publish statistical information relating to the commercial, industrial, financial, social, economic and general activities and condition of the Canadian people.
Purpose	To provide data on the social and economic conditions of Aboriginal people in Canada. Specifically, to focus on issues of importance to Aboriginal people such as health, language, employment, income, schooling, housing, and mobility. ☐ Public Health & Surveillance: ☐ screening ☐ immunization ☐ communicable disease ☐ other ☐ Operating a Health Organization or System: ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability ☒ Research: ☒ population ☐ clinical ☐ program/service ☒ public policy ☐ Service Delivery: ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data ☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers ☒ First Nation/North American Indian: ☒ Status (registered, treaty) ☒ Non-status ☐ On-reserve ☒ Off-reserve ☐ Band name or number ☒ Inuit/Inuk: ☒ Inuvialuit ☒ Nunavut ☒ Nunavik ☒ Nunatsiavut ☒ Métis: ☐ On Métis register ☒ Other Métis identity and/or ancestry ☒ Aboriginal: ☐ Other Specify The target population for the 2006 APS is composed of the Aboriginal population in Canada living in private dwellings, 6 years of age and older as of October 31, 2006. In the provinces, people living in Indian Settlements or on reserve were excluded from the APS however, in the territories, all Aboriginal people were included.
Status & Update	Database status Active Database update frequency Ongoing / on regular frequency Frequency of Updates: Quinquennial (5 year)
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1991 Month/year of latest available ethno-cultural identifiers: 2006
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One

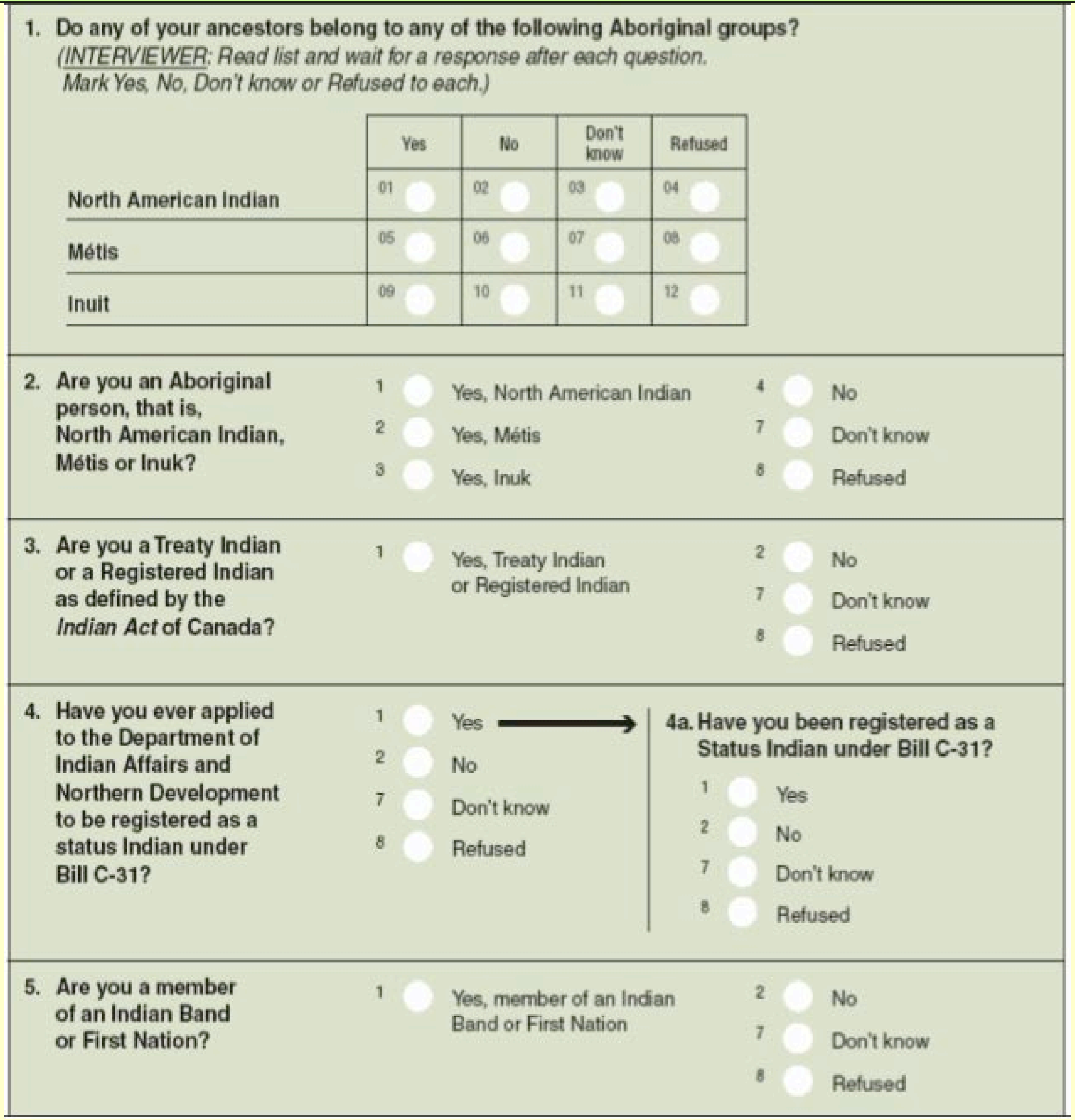
I. DATABASE – Aboriginal Peoples Survey

Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☒ Other Specify:	
	Dissemination Area	
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease	
Users	Primary users of this database - Statistics Canada staff, policy makers, multidisciplinary researchers	
	Database also used by users external to Custodian	
Populations	Population groups included in this database – First Nations, Inuit and Métis aged 6 years and older who, in the case of First Nations in provinces, reside off reserve (the latter as of APS 2006; before 2006 First Nations on reserve were included). The Aboriginal Peoples Survey had four questionnaires: Adult Core (people aged 15 and older); Children and Youth (people aged 6 to 14); Métis Supplement (adults who identified as Métis or who had Métis ancestry); and Arctic Supplement (adults living in Inuit regions). In 2001 and 1991, all ages were surveyed.	
	Population Coverage - % of population targeted by the database that has been captured: N/A	
	Alternatively, sample with weights? Yes. If yes, sample size ~3.5% of total First Nation, Inuit and Métis population in 2006	
Records	Total # of records in database: 45,177 in 2006	Annual number of records collected/updated: 1991: 81,570 respondents 2001: 95,994 respondents 2006: 45,177 respondents
Contact/ Questions	Support Organization Aboriginal Statistics Program, Statistics Canada Title of person in support role: Analyst Name: Ron Cunningham Phone: 613-951-5758 E-mail: Ron.Cunningham@statcan.gc.ca	
Web site	http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3250&lang=en&db=imdb&adm=8&dis	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Below are the questions from the 2006 APS. For previous years refer to: 1. Social and Aboriginal Statistics Division. How Statistics Canada Identifies Aboriginal Peoples. Ottawa: Statistics Canada 2007. Catalogue No.: 12-592-XIE.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE



1. Do any of your ancestors belong to any of the following Aboriginal groups?
(INTERVIEWER: Read list and wait for a response after each question. Mark Yes, No, Don't know or Refused to each.)

	Yes	No	Don't know	Refused
North American Indian	01 ○	02 ○	03 ○	04 ○
Métis	05 ○	06 ○	07 ○	08 ○
Inuit	09 ○	10 ○	11 ○	12 ○

2. Are you an Aboriginal person, that is, North American Indian, Métis or Inuk?

1 ○ Yes, North American Indian
2 ○ Yes, Métis
3 ○ Yes, Inuk
4 ○ No
7 ○ Don't know
8 ○ Refused

3. Are you a Treaty Indian or a Registered Indian as defined by the *Indian Act* of Canada?

1 ○ Yes, Treaty Indian or Registered Indian
2 ○ No
7 ○ Don't know
8 ○ Refused

4. Have you ever applied to the Department of Indian Affairs and Northern Development to be registered as a status Indian under Bill C-31?

1 ○ Yes → 4a.
2 ○ No
7 ○ Don't know
8 ○ Refused

4a. Have you been registered as a Status Indian under Bill C-31?

1 ○ Yes
2 ○ No
7 ○ Don't know
8 ○ Refused

5. Are you a member of an Indian Band or First Nation?

1 ○ Yes, member of an Indian Band or First Nation
2 ○ No
7 ○ Don't know
8 ○ Refused

Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Question Design	Reason why the above question and/or identifier was chosen: Ethnocultural identity questions in the APS are largely based on the questions that serve the same purpose on the 2006 census. In the Aboriginal Peoples Survey, three Aboriginal group-specific questions are asked regarding North American Indian, Métis and Inuit ancestries. The content and flow of questions used in the Census and consequently the APS are designed to describe and capture fluid aspects of ethno-cultural identification while maximizing response rate, maximizing the yield of valid and usable information and respecting the need to differentiate between First Nations, Inuit and Métis. For practical reasons, some differences between the two sources do exist. For example, the Census uses an open-ended ethnic origin question ("What were the ethnic or cultural origins of this person's ancestors?"). The comparable question in the APS is included above (Question 1).
	Ethno-cultural identity question(s) has been tested Yes Test report re question design is available Yes Name/citation for test report: 1. Social and Aboriginal Statistics Division. Report on Regional Discussions on Aboriginal Identification Questions. Ottawa: Statistics Canada 2008. Catalogue No.:89-629-X 2. Parent M, Lathe H. Testing for the 2011 Census of Canada. Statistics Canada Symposium 2008: Data Collection: Challenges, Achievements and New Directions. Statistics Canada; 2009. Catalogue No.: 92-140-XWE 3. Social and Aboriginal Statistics Division. Aboriginal Peoples Technical Report, 2006 Census, Second Edition. Ottawa: Statistics Canada 2010. Catalogue No.: 92-569-X 4. Social and Aboriginal Statistics Division. Aboriginal Peoples Survey, 2006: Concepts and Methods Guide. Ottawa: Statistics Canada 2009. Catalogue No.: 89-637-X
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: To maximize response rate and validity, the Aboriginal Peoples Survey was translated into 20 Aboriginal languages and interpreters were hired. Translators were hired when requests were received for the survey to be conducted in other Aboriginal languages. In terms of mode of collection, the survey was conducted using personal interviews in Inuit regions, Labrador and in the Northwest Territories (except Yellowknife). Telephone interviews were conducted elsewhere in Canada. In a number of locations, personal interviews were undertaken when people could not be reached by telephone. The resulting information, which is not available elsewhere, can be used to answer a wide range of questions of importance to First Nations, Inuit and Métis peoples. The size (> 45,000 respondents for the 2006 APS), coverage, and repetition of the APS give it advantages over other data sources. The large sample size enables statistically stable estimates to be made for subgroups of the population. The inclusion of respondents from all provinces and territories allow geographic comparisons to be made across the country. Furthermore, the use of the census as a sampling frame enables the inclusion of some typically under-represented groups, such as urban Aboriginal people, non-status First Nations, off-reserve First Nations, and Métis. The repetition of the survey over time enables the examination of trends over time and provides an opportunity to estimate future burden.
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Yes Test /pilot/ evaluation report is available Yes Title/ citation for report: See references under Question Design

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Linkage	Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Statistics Canada defines data quality as a degree or level of confidence that the data are "fit for use", relating to relevance, accuracy, timeliness, accessibility, interpretability and coherence. Indicators of data quality range from sampling errors to non-sampling errors, and include coverage, response rate, response error and processing errors, among others. These are detailed in Aboriginal Peoples Survey, 2006: Concepts and Methods Guide. 1. Social and Aboriginal Statistics Division. Aboriginal Peoples Survey, 2006: Concepts and Methods Guide. Ottawa: Statistics Canada 2009. Catalogue No.: 89-637-X no. 003	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes
	Title/citation for test/pilot/quality evaluation report: See below.	
	The APS, Census and their Aboriginal identifiers are under constant review. The interpretation, usability as well as limitations of the data are well-documented. For further information, see citations below. 1. Social and Aboriginal Statistics Division. How Statistics Canada Identifies Aboriginal Peoples. Ottawa: Statistics Canada 2007. Catalogue No.: 12-592-XIE. 2. Guimond E. Fuzzy definitions and population explosion: changing identities of Aboriginal groups in Canada. Not strangers in these parts: urban Aboriginal peoples Ottawa (ON): Policy Research Initiative. 2003:35-49. 3. Guimond E. Ethnic mobility and the demographic growth of Canada’s aboriginal populations from 1986 to 1996. Current Demographic Trends. 1999:190-1.	
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No	
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: The future of the APS will depend on the quality of the data collected by the National Household Survey, which would form the source of the sample for future cycles of the APS. The APS is conducted on a cost-recovery basis.	

III. DATA ACCESS

Privacy Constraints

All personal information created, held or collected by Statistics Canada is protected by the Privacy Act and by the Statistics Act.

A Privacy Impact Assessment has been done for this database Select One

Information has been used for secondary purposes Yes
If yes, examples of secondary data use: Numerous researchers, policy makers and Aboriginal groups have used the APS aggregate data.

First Nations, Inuit, and/or Métis Engagement

First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes
An MOU or formal agreement governing development and/or use of the database is in place Not Applicable
First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as
☒ Designer (e.g. of question) | ☒ Collector of data | ☐ Custodian | ☐ Analyst | ☒ User for decisions

Representatives of Aboriginal organizations were involved in the design and implementation of the 2006 Aboriginal Peoples Survey (APS) through participation in the Implementation Committee. Aboriginal interviewers were hired as much as possible.

The Aboriginal Peoples Survey Implementation Committee is a unique forum bringing together representatives from national Aboriginal organizations, federal departments, provinces and territories. Representatives from the Congress of Aboriginal Peoples, the Inuit Tapiriit Kanatami, the Métis National Council, the National Association of Friendship Centres, the Native Women's Association of Canada, and an Elder / facilitator were involved in the development and implementation of the survey and continue to be involved in disseminating the data. The Assembly of First Nations was an active member until the spring of 2001.

OCAP

The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:
First Nations OCAP principles No | Inuit Land Claims research protocols Select One | Métis requirements Select One

IV. DATA USE & REPORTING

Data Products

Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes
Examples of analyses, reports, publications:

1. 1991 APS informed the Royal Commission on Aboriginal Peoples (RCAP). RCAP used the data as a primary source of demographic, social and economic data for their final report and related research studies (http://www.collectionscanada.gc.ca/webarchives/20071115053257/http://www.ainc-inac.gc.ca/ch/rcap/sg/sgmm_e.html)
2. Peer-reviewed publications based on the APS have been published examining, for example, social determinants of health, income inequality, educational achievement. Provincial and territorial reports have been published

See here for Statistics Canada publications resulting from the APS: http://www.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=89-637-X&chropg=1&lang=eng

Evidence-informed Decisions

The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes

Examples of evidence-informed decisions:

1. The APS informed the recommendation of the Royal Commission on Aboriginal Peoples.
2. APS reports have helped practitioners, policy makers and researchers move forward on their agendas in a range of policy areas i.e. Métis health, Inuit health, education (i.e. school experiences of off-reserve First Nations children) and country food harvesting.

Reporting

Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes

Measures are taken to provide the greatest possible access to the statistical output from the survey to the First Nation, Inuit and Métis groups. Each of the National Aboriginal Organizations (NAOs) has a Statistics Canada analyst assigned as a liaison to facilitate the flow of information at all points in the survey cycle. Each NAO receives an allotment of "free hours" of custom tabulations of APS data.

IV. DATA USE & REPORTING

Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Statistics Canada is a national resource to federal, provincial/territorial and other jurisdictions on the topic of ethno-cultural identification, based on its long history of experience and expertise in developing and administering surveys and analyzing and interpreting the resulting information. While recognizing that ethno-cultural identification is fluid at any point in time, and subject to change over time, the approach taken in the APS and the Census are frequently the starting point for jurisdictions wishing to develop their own survey tools.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: The questions used to identify First Nations, Inuit and Métis on the census and similarly the APS, capture multiple dimensions of Aboriginal ethno-cultural identification i.e. Status/Treaty, On/Off-reserve, Ancestry/Identity. Accordingly, this identifier is "high resolution" compared to a more simple Aboriginal identifier. Furthermore, an advantage of the APS approach is the comparability of the measure historically, since questions have remained relatively consistent over time. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: The five questions used to identify First Nation, Inuit and Métis people on the APS have a relatively larger burden on the interviewer and respondent than potentially simpler questions.

5.7.2 Canadian Community Health Survey (CCHS)

I. DATABASE – Canadian Community Health Survey (CCHS)				
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	The CCHS is a cross-sectional survey that collects information related to health status, health care utilization and health determinants for the Canadian population every two years. It relies upon a very large sample of respondents across Canada, and is designed to provide reliable estimates for the general population at the health region level.			
Custodian	Statistics Canada			
	Mandate of Custodian: To collect, compile, analyse, abstract and publish statistical information relating to the commercial, industrial, financial, social, economic and general activities and conditions of the Canadian people.			
Purpose	The central objective of the CCHS is to gather health-related data at the sub-provincial levels of geography (health region or combined health regions). The specific aims of the CCHS are to: • Support health surveillance programs by providing health data at the national, provincial and intra-provincial levels; • Provide a single data source for health research on small populations and rare characteristics; • Timely release of information easily accessible to a diverse community of users; • Create a flexible survey instrument that includes a rapid response option to address emerging issues related to the health of the population.			
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☒ other Chronic disease	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☐ Research ☒ population ☐ clinical ☐ program/service ☒ public policy	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☒ First Nation/North American Indian	☒ Inuit/Inuk	☒ Métis	☒ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☒ Other Identity and/or ancestry	☐ Other Specify
	The database includes information on First Nations, Inuit and Métis people on the basis of "ancestry" as well as "self-identification". While the database includes Status and non-Status First Nations, it does not ask any question that differentiates between the two.			
Status & Update	Database status Active	Database update frequency Ongoing / on regular frequency Frequency of Updates: Annual		
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 2001	Month/year of latest available ethno-cultural identifiers: 2010		
Level of Detail	1. Individual Record 2. If Individual Record was selected: Identifiable 3. If Not identifiable was selected: Select One			

I. DATABASE – Canadian Community Health Survey (CCHS)

Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Postal Code
Service Domain	☒ Acute Care ☒ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☒ Home & Community Care ☒ Primary Care ☒ Drugs ☒ Cancer ☒ Diabetes ☐ Renal Dialysis ☒ Immunization ☒ Communicable Disease
Users	Primary users of this database - Federal and provincial departments of health and human resources, social service agencies, and other types of government agencies use the information collected from respondents to monitor, plan, implement and evaluate programs to improve the health of Canadians. The data generated from the CCHS is also commonly used by health regions and public health units to inform policy and programming. Researchers from various fields use the information to conduct research to improve health. Non-profit health organizations and the media use the CCHS results to raise awareness about health. Database also used by users external to Custodian
Populations	Population groups included in this database – The target population of the CCHS is all Canadians aged 12 and over. Excluded from the sampling frame are individuals living on Indian Reserves and on Crown Lands, institutional residents, full-time members of the Canadian Forces, and residents of certain remote regions. The sampling methodology was designed to ensure over–representation of youth under 19 years of age and seniors 65 years of age and older. Population Coverage - % of population targeted by the database that has been captured: Alternatively, sample with weights? Yes. If yes, sample size ~ 65,000
Records	Total # of records in database: 3200 respondents reported Aboriginal Identity Annual number of records collected/updated: ~65,000
Contact/ Questions	Support Organization Statistics Canada Title of person in support role: Assistant Director Name: Health Statistics Division Phone: (613) 951-9416 E-mail: Marie.Patry@a.statcan.gc.c
Web site	http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3226&lang=en&db=imdb&adm=8&dis=2

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): From 2012 Questionnaire: **A. Are you an Aboriginal person, that is, First Nations, Métis or Inuk (Inuit)? First Nations includes Status and Non-Status Indians.** INTERVIEWER: The terms "First Nations" and "North American Indian" can be interchanged. Some respondents may prefer one term over the other. "Inuit" is the plural form of "Inuk". 1. Yes → Go to B 2. No 3. Don’t Know 4. Refuse This question should be answered regardless of whether or not this person is an Aboriginal person of North America.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Aboriginal people are usually those with ancestors who resided in North America prior to European contact and who identify with one of the three Aboriginal groups listed on the questionnaire: First Nations (North American Indian), Métis and Inuk. Persons who consider themselves to be East Indian or Asian Indian, or who have ethnic roots on the subcontinent of India, should respond: "No, not an Aboriginal person" to this question. Individuals who refer to themselves as Métis in the context of mixed ancestry, but who do not have North American Aboriginal ancestry-for example, those from Africa, the Caribbean and South America-should respond "No, not an Aboriginal person". INTERVIEWER: If the respondent has already specified the Aboriginal group(s), select the group(s) from the list below; if not, ask: **B. ARE YOU First Nations, Métis or Inuk (Inuit)?** INTERVIEWER: Mark all that apply. First Nations (North American Indian) includes Status and Non-Status Indians. The terms "First Nations" and "North American Indian" can be interchanged. Some respondents may prefer one term over the other. "Inuit" is the plural form of "Inuk". . 1. First Nations (North American Indian) 2. Métis 3. Inuk (Inuit) 4. Don't Know → Go to C 5. Refuse → Go to C **C.** You have entered "Don't know" or "Refusal". Respondents sometimes get confused with the terminology used to describe different Aboriginal groups. If you wish to change the entry, return to question B and enter the appropriate answer. Otherwise, please confirm. Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached
Question Design	Reason why the above question and/or identifier were chosen: Ethno-cultural questions in the CCHS are based on those used in the Long Form Census. As such, each component of the CCHS questionnaire is developed in collaboration with specialists from Statistics Canada, other federal and provincial departments and/or academic fields. Like the Census, the content and flow of questions used in the CCHS are designed to describe and capture fluid aspects of ethno-cultural identification while maximizing response rate, maximizing the yield of valid and usable information and respecting the need to differentiate between First Nations, Inuit and Métis. In order to decrease the response burden, questions pertaining to band membership and Status are not included in the CCHS, unlike the Census.
	Ethno-cultural identity question(s) has been tested Yes Test report re question design is available Yes Name/citation for test report: The questions in the CCHS arise from those used in the long form census. Examples of some test reports are listed below: 1. Social and Aboriginal Statistics Division. Report on Regional Discussions on Aboriginal Identification Questions. Ottawa: Statistics Canada 2008. Catalogue No.:89-629-X 2. Parent M, Lathe H. Testing for the 2011 Census of Canada. Statistics Canada Symposium 2008: Data Collection: Challenges, Achievements and New Directions. Ottawa: Statistics Canada 2009. Catalogue No.: 92-140-XWE

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	3. Social and Aboriginal Statistics Division. Aboriginal Peoples Technical Report, 2006 Census, Second Edition. Ottawa: Statistics Canada 2010. Catalogue No.: 92-569-X 4. Marketing Division. 2006 Census Content Consultation Report. Ottawa: Statistics Canada 2004. Catalogue No.:92-130-XIE	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: The CCHS is the most inclusive national, population-based, health survey. Unlike aboriginal-specific surveys, it allows for uniform collection of data across aboriginal and non-aboriginal populations and accordingly, provides a metric by which aboriginal groups can consider their own health status. Furthermore, the population-wide nature of this survey results in the inclusion of some typically under-represented groups, such as urban Aboriginals, off-reserve First Nations, and Métis. The repetition of the survey enables the examination of trends over time.	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Yes Test /pilot/ evaluation report is available Yes Title/ citation for report: St-Pierre, M. et Béland, Y. (2004). «Mode effects in the Canadian Community Health Survey: a Comparison of CAPI and CATI», 2004 Proceedings of the American Statistical Association Meeting, Survey Research Methods. Toronto, Canada: American Statistical Association.	
Data Linkage	Potential, i.e. "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Answer 1. 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes
	Data quality indicators that are used: Statistics Canada defines data quality as a degree or level of confidence that the data are "fit for use", relating to relevance, accuracy, timeliness, accessibility, interpretability and coherence. Indicators of data quality range from sampling errors to non-sampling errors, and include coverage, response rate, response error and processing errors, among others. E.g., the response rate to the survey was between 71% and 73% for 2009 and 2010. Further quality indicators are detailed in Canadian Community Health Survey User's Guide: 1. Statistics Canada. Canadian Community Health Survey Annual Component; User Guide 2010 and 2009-2010 Microdata files. Ottawa: Statistics Canada 2011.	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes
	Title/citation for test/pilot/quality evaluation report: The CCHS, Census and the aboriginal identifiers used in each are under constant review. The interpretation, usability as well as limitations of the data are well-documented. For further information, see citations below. 1. Social and Aboriginal Statistics Division. How Statistics Canada Identifies Aboriginal Peoples. Ottawa: Statistics Canada 2007. Catalogue No.: 12-592-XIE. 2. Guimond E. Fuzzy definitions and population explosion: changing identities of Aboriginal groups in Canada. Not strangers in these parts: urban Aboriginal peoples Ottawa (ON): Policy Research Initiative. 2003:35-49. 3. Guimond E. Ethnic mobility and the demographic growth of Canada's aboriginal populations from 1986 to 1996. Current Demographic Trends. 1999:190-1.	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: Unlike the APS, the CCHS does NOT use the long-form census as a sampling frame. This has two major implications. The first implication is that Aboriginal populations are not over-sampled. This can result in small sample sizes for subgroup analyses and accordingly, prevalence estimates that may not be stable at the subgroup-level. The second implication is that the collection of ethno-cultural identifiers is not dependent on the former Long Form Census, and will therefore be unaffected by its now non-mandatory nature.

III. DATA ACCESS

Privacy Constraints	All personal information created, held or collected by Statistics Canada is protected by the Privacy Act and by the Statistics Act
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: Numerous researchers, policy makers and Aboriginal groups have used the CCHS data.
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☒ Analyst ☐ User for decisions
	First Nations, Inuit and Métis were not explicitly consulted on the design or collection in the CCHS. However, they have been consulted on the design of the ethno-cultural questions for use in the Census and APS, and by virtue of that, contributed to the design of these questions. 1. Social and Aboriginal Statistics Division. Report on Regional Discussions on Aboriginal Identification Questions. Ottawa: Statistics Canada 2008. Catalogue No.:89-629-X
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Lix LM, Bruce S, Sarkar J, Young TK. Risk factors and chronic conditions among Aboriginal and non-Aboriginal populations. Health Reports. Ottawa: Statistics Canada 2009. Catalogue No.:82-003-X 2. Deering KN, Lix LM, Bruce S, Young TK. Chronic Diseases and Risk Factors in Canada's Northern Populations: Longitudinal and Geographic Comparisons. Canadian Journal of Public Health 2009;100(1):14-17. For a list of research projects completed based on the CCHS, go here: http://www.statcan.gc.ca/rdc-cdr/proje_cchs-escc-eng.htm
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: CCHS reports have helped practitioners, policy makers and researchers move forward on their policy agendas in a range of health areas. For example, in June 2010, the Manitoba Centre for Health Policy in Collaboration with the Manitoba Métis Federation published a report entitled "Profile of Métis Health Status and Healthcare Utilization in Manitoba: A population-based study" 1. Martens P, Bartlett J, Burland E, Prior H, Burchill C, Huq S, et al. Profile of Métis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study: University of Manitoba. Manitoba Centre for Health Policy 2010. Report No.: 1896489532.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Aboriginal identifiers are not included in the Public Use Microdata File for confidentiality purposes. To have access to the Aboriginal Identity variable, Aboriginal groups (like the general public) must apply for access to the data file through a research data centre (RDC).
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Yes Statistics Canada is a national resource to federal, provincial/territorial and other jurisdictions on the topic of ethno-cultural identification, based on its long history of experience and expertise in developing and administering surveys and analyzing and interpreting the resulting information. While recognizing that ethno-cultural identification is fluid at any point in time, and subject to change over time, the approach taken in the CCHS and the Census are frequently the starting point for jurisdictions wishing to develop their own survey tools.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: The questions used to identify First Nations, Inuit and Métis on the census and similarly the CCHS, capture both the identity and ancestry dimension of Aboriginal ethno-cultural identification. Furthermore, an advantage of the CCHS approach is the comparability of the measure historically, since ethno-cultural questions have remained relatively consistent over time. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Unlike the APS and Census, the CCHS does not differentiate between Status and non-Status Indians, a differentiation which may be important in some settings.
Additional Comments	Statistics Canada intends to publish a technical report in the upcoming year that will comment on the robustness of the CCHS to yield stable estimates within the Aboriginal population in Canada. The validity and potential consequences of and best practices for combining cycles of the CCHS (in order to increase the available sample size) will be considered and outlined. This report will be in keeping with the priorities of Statistics Canada, which include maximizing the usability of existing data.

5.7.3 1991 Canadian Census Cohort: Mortality, Cancer and Residential Mobility Follow-up Study

I. DATABASE – 1991 Canadian Census Cohort: Mortality, Cancer and residential mobility follow-up study	
Geography	☒ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	The file is a recently updated linkage of four national databases. The source files include the 1991 Census of the Population (long form), Canadian Mortality Database (CMDB), the Canadian Cancer Database (CCDB) and annual tax summary files (TSF) (non-financial data).
Custodian	Statistics Canada
	Mandate of Custodian: To produce statistics that help Canadians better understand their country—its population, resources, economy, society and culture.
Purpose	The cohort was initially designed to develop a set of baseline indicators of mortality for monitoring health disparities in Canada. In 2009, approval to extend the cohort to include an additional 10 years of mortality data (to 2011), an additional 20 years of TSF (to 2012) and expanded data holdings to include cancer incidence (from 1969 to 2011) was granted in order to assess the impact of long-term exposure to air pollution on human health.
	☒ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☒ other Mortality, Cancer
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☐ program/service ☒ public policy
	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☒ Band name or number
	☒ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☒ Other Métis ancestry
	☐ Aboriginal ☐ Other Specify
	The identity concept was not included in the 1991 Census, and accordingly definitions of First Nations and Métis are based on report of North American Indian and/or Métis ancestry, Registered Indian Status and/or membership in a North American Indian Band or First Nation. Inuit ancestry is also asked.
Data Sources	1. 1991 Canadian Census of the Population (Long Form) 2. Canadian Mortality Database (1991-2011) 3. Canadian Cancer Database (1969-2011) 4. Annual Tax Summary files (1990-2012)
	The linked Census-mortality-tax-cancer incidence file is an extension of the initial Census-mortality file. Methods of linkage for each file are described briefly below. CENSUS-MORTALITY FILE: Because the 1991 Census data files did not contain names, but names were needed to identify corresponding deaths, creation of the initial Census-mortality database required two linkages. First, the Census file was linked to a nominal list (name) file abstracted from tax-filer data in 1990 and 1991 and then encrypted. Then, the Census plus encrypted name file was matched to the Canadian Mortality Database using methods of probabilistic record linkage, an approach similar to that used for other mortality follow-up studies at Statistics Canada. The resulting census-mortality file contains anonymous information on, among others, demographic characteristics, socio-economic status, activity limitations and disability for all cohort members and, for individuals who died during the study period, cause and date of death.

I. DATABASE – 1991 Canadian Census Cohort: Mortality, Cancer and residential mobility follow-up study

	CENSUS-MORTALITY-TAX-CANCER INCIDENCE FILE: In an extension of the census-mortality file, the cohort was linked to TSF from 1990 to 2007. This serial linkage of tax files allows investigators to consider place of residence annually, which will be important in the study of, for example, air pollution. The linked file was also probabilistically linked to the CMDB (anticipated linkage until 2011) and the CCDB (1969 to 2011 anticipated) following procedures routinely employed for mortality follow-up studies at Statistics Canada.
Availability	Month/year of earliest available ethno-cultural identifiers: June 1991 Month/year of latest available ethno-cultural identifiers: June 1991
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☒ National ☒ Province/Territory ☒ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☒ Other Specify
	Postal Code
Service Domain	☐ Acute Care ☐ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☐ Mental Health/Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☐ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Population health researchers
	Database also used by users external to Custodian
Populations	Population groups included in this database – A 15% sample (n=2.7 million) of the non-institutionalized Canadian population aged 25 years or older on Census Day (June 4th, 1991)
Records	Total # of records in database: 2.7 million Canadians, incl. 11,800 Métis and 56,700 Registered Indians.
Contact/Questions	Support Organization Statistics Canada Title of person in support role: Chief, Health Analysis Division Name: Michael Tjepkema Phone: 613-951-3896 E-mail: Michael.Tjepkema@statcan.gc.ca
Web site	www.statcan.gc.ca

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/gaps that have been addressed: The varying methods used to identify First Nations, Inuit and Métis within Canada have typically limited research to provincial/territorial or regional boundaries and have made it challenging to distinguish real differences across the country from those that may have arisen as a result of different methods employed. These regional analyses are often limited by a lack of sufficient power to identify important temporal and site-specific patterns of disease. This linkage provides an opportunity to consider the health of First Nations, Inuit and Métis across the country, with the same methodology used to identify individuals and health outcomes as in the general population. This database also benefits from the use of the census as its source file for First Nations and Métis identifiers, which is not limited to Status, on-reserve or registered individuals.

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Data Quality	It is estimated that 3.4% of the Canadian population was missed on Census day, and therefore rendered ineligible for the long-form. Missed individuals tended to be younger, to be more mobile, to have lower income and were more likely to have Aboriginal ancestry, or be homeless. The net under-coverage is expected to have minimal influence on findings from this cohort, however, as most of it is accounted for by individuals less than 25 years of age. Individuals were excluded from the cohort if their Census response could not be matched to a tax record in either 1990 or 1991. First Nations and Métis Census respondents were less likely to be linked to a tax-filing than non-aboriginal Census respondents. This is likely to be, at least in part, due to the fact that Registered Indians are entitled to a tax exemption under section 87 of the Indian Act for income earned or considered to be earned on a reserve. A comparison of First Nations and Métis cohort members (i.e. those who had a matching tax-filing) to all eligible First Nations and Métis Census respondents suggested that the demographics and socio-economic profile of linked and non-linked First Nations and Métis were similar, suggesting that linkage bias, if present, is minimal. Inuit analysis using the original file (follow-up to 2001) is not recommended since ascertainment of mortality is likely underestimated compared to other cohort members.
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes By using a large, validated sample with long term consistent data collection (Census) and linking it to the Canadian Cancer Database and the Canadian Mortality Database, it is possible to cost-effectively assess the patterns in mortality and cancer on ethno-cultural populations that are not otherwise captured in these databases.

III. DATA ACCESS

Privacy Constraints	The Statistics Canada data holdings for this project are collected under different legislative mandates. The use of the data is governed by the Statistics Act. A Privacy Impact Assessment has been done for this database Select One
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database No An MOU or formal agreement governing development and/or use of the database is in place No First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions The creation of the database was approved the Statistics Canada Policy Committee after consultations with Statistics Canada Confidentiality and Legislation Committee, the Data Access and Control Services Division, and the Federal Privacy Commissioner. It was approved by the Research Ethics Committee of the University of Toronto, and was peer-reviewed by the Canadian Population Health Initiative, the Canadian Institutes of Health Research, and the Research Advisory Council of the Ontario Workplace Safety and Injury Board. All publications relevant to First Nations and Métis arising from the use of the database are institutionally reviewed prior to publication through Statistic Canada's Social and Aboriginal Statistics Division to ensure analysis is culturally appropriate. Social and Aboriginal Statistics Division consults with Aboriginal organizations during this process.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles No | Inuit Land Claims research protocols No | Métis requirements No

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: Little information has been published about the mortality of the Métis people of Canada. The database has already served to describe mortality patterns among Métis and Registered Indian adults, compared with the non-Aboriginal population: • Tjepkema M, Wilkins R, Senécal S, Guimond E, Penney C. Mortality of Métis and registered Indian adults in Canada: an 11-year follow-up study. Health Reports 2009 Dec;20(4):31-51. • Tjepkema M, Wilkins R, Senécal S, Guimond E, Penney C, Potential years of life lost at ages 25 to 74 among Métis and non-Status Indians in Canada: 11-year follow-up study Health Reports 2011 22(3). • Tjepkema M, Wilkins R, Pennock J, Goedhuis N, Potential years of life lost at ages 25 to 74 among Status Indians living on and off reserve, 1991-2001 Health Reports 2011 22(3). • Tjepkema M, Wilkins R, Senécal S, Guimond E, Penney C, Mortality of urban Aboriginal adults in Canada, 1991-2001 Chronic Diseases in Canada 2010 Dec;31(1): 4-21 (Co published in Prev Chronic Dis. 2011 Jan;8(1):A06.). • Tjepkema M, Wilkins R, Remaining life expectancy at age 25 and probability of survival to age 75, by socio-economic status and Aboriginal ancestry Health Reports 2011 22(4).
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: The findings of the already published reports have shed light on inequalities in life expectancy between Aboriginal and non-Aboriginal populations in Canada. This information is likely to inform practice, policy and research decisions. Furthermore, the success and usefulness of the initial linkage resulted in the extension of the linkage to include more data holdings over a greater follow-up period.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Reports are published and shared publicly. Several presentations have been given at Aboriginal conferences and meetings.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One The project is national in scope, with provincial break-outs where the numbers allow. Both the approach and results are expected to inform research and policy decisions in other jurisdictions.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: 1) The strong history of experience/ expertise in record linkage at Statistics Canada, 2) Statistics Canada being the custodian of all the databases involved. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: 1) Funding (it is expensive to do record linkage at Statistics Canada) 2) Replacement of the mandatory long form census with the National Household Survey may affect the generalizability of future linkages based on the National Household Survey.
Additional Comments	

5.7.4 Census - Long Form

I. DATABASE – Census 2B Long-form (before 2011)	
Geography	☒ Canada ☒ BC ☒ AB ☒ SK ☒ MB ☒ ON ☒ QC ☒ NB ☒ NS ☒ PE ☒ NL ☒ YK ☒ NT ☒ NV ☒ Other Communities
Description	The census provides a statistical portrait of our country and its people by collecting important information about the social and economic situation of the people living in its various regions. In Canada, the census is the only reliable source of detailed data for small groups (e.g. lone-parent families, ethnic groups) and for areas as small as a city neighbourhood or as large as the country itself. Because the Canadian census is collected every five years and the questions are similar, it is possible to consider changes that have occurred in the make-up of Canada's population over time. Prior to 2011, the ethno-cultural and Aboriginal identity questions appeared on the long form of the Census. In general, 1 in 5 households (20%) were asked to complete the census long form (2B questionnaire) and 4 out of 5 households (80%) were to complete the census short form (2A questionnaire). In the Yukon, the Northwest Territories (with the exception of Whitehorse and Yellowknife), Nunavut, and Indian reserves, Indian settlements, Indian government districts and 'terres réservées,' however, the census long form (2D questionnaire) was administered to every household. The short form census contained 8 questions on basic topics such as relationship to other household members, age, sex, marital status, and mother tongue. The long form census contained the eight questions from the short form plus 53 additional questions on topics such as Aboriginal identification, education, ethnicity, mobility, income, employment and dwelling characteristics. In 2011, the long form census was replaced by the voluntary National Household Survey (NHS). For more information, go to: http://www12.statcan.gc.ca/nhs-enm/index-eng.cfm
Custodian	Statistics Canada
	Mandate of Custodian: To collect, compile, analyse, abstract and publish statistical information relating to the commercial, industrial, financial, social, economic and general activities and condition of the Canadian people.
Purpose	The census is more than a population count: it provides all levels of government, business, industry, media, academia and independent organizations with social, economic and demographic information that is essential for making decisions regarding the many services each provides to the public.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☐ program/service ☒ public policy
	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☒ Band name or number
	☒ Inuit/Inuk ☒ Inuvialuit ☒ Nunavut ☒ Nunavik ☒ Nunatsiavut
	☒ Métis ☐ On Métis register ☒ Other Métis identity and/or ancestry
	☒ Aboriginal ☒ Other Ancestry only
Status & Update	Database status Active
	Database update frequency Ongoing / on regular frequency Frequency of Updates: Quinquennial (5 year)

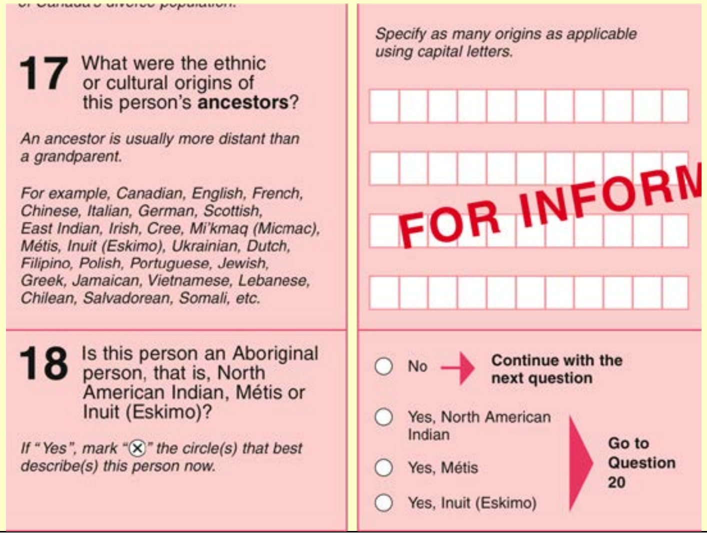
I. DATABASE – Census 2B Long-form (before 2011)

Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): An ethnic origin question has been asked in the census since 1871. However, the question has undergone several changes over the years. The areas that underwent changes involved the criteria used to determine ethnic origin or ancestry, the terminology used to designate Aboriginal peoples, as well as changes to the question itself, and to the way the data have been collected. Prior to 1951, Aboriginal people in Canada were defined by their tribal descent or their matrilineal descent (from the mother's side). This changed between 1951 and 1971 when Aboriginal people were defined by their patrilineal descent (from the father's side). From 1981 to the present, Aboriginal ancestry has been defined by descent from both the mother's and the father's side. In addition, since then, the ethnic origin question has allowed for the reporting of single and multiple responses. Prior to 1981, only single responses were permitted. Also, starting in 1996, questions on Aboriginal identity, Registered or Treaty Indian status, and Membership in an Indian Band or First Nation have been used to derive the concept of Aboriginal Identity, which is used in most census products. Month/year of latest available ethno-cultural identifiers: May/2006
Level of Detail	1. Individual Record 2. If Individual Record was selected: Not identifiable 3. If Not identifiable was selected: Non reversible
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☒ National ☒ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☒ Local (e.g. facility) ☒ Other Custom geographies
	Postal Code
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - Statistics Canada staff, governments, businesses, researchers and individual Canadians
	Database also used by users external to Custodian
Populations	Population groups included in this database – Canadian citizens (by birth or by naturalization) and landed immigrants with a usual place of residence in Canada; Canadian citizens (by birth or by naturalization) and landed immigrants who are abroad, either on a military base or attached to a diplomatic mission; Canadian citizens (by birth or by naturalization) and landed immigrants at sea or in port aboard merchant vessels under Canadian registry; persons with a usual place of residence in Canada who are claiming refugee status and members of their families living with them; persons with a usual place of residence in Canada who hold Study Permits and members of their families living with them; persons with a usual place of residence in Canada who hold Work Permits and members of their families living with them.
	Population Coverage - % of population targeted by the database that has been captured: Prior to 2011, in the general population, approximately 1 in 5 households were enumerated using the long-form questionnaire. On reserves and in remote areas, all residents were enumerated using the long form. In 2011, the long form census was replaced by the National Household Survey. For more information, go to: http://www12.statcan.gc.ca/nhs-enm/index-eng.cfm
	Alternatively, sample with weights? Yes. If yes, sample size ~20%
Records	Total # of records in database: In 2006, 1.68 million people reported Aboriginal ancestry. In the same year, 1.17 million people reported Aboriginal identity. (See below for a description of each concept) Annual number of records collected/updated: Refer to the information at the following link: http://www12.statcan.gc.ca/census-recensement/2006/ref/rp-guides/rp/coverage-couverture/cov-couv_index-eng.cfm

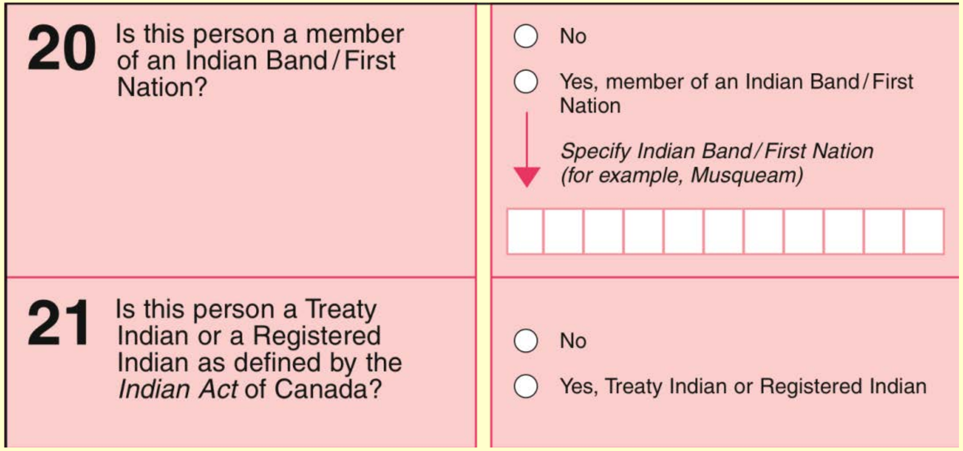
I. DATABASE – Census 2B Long-form (before 2011)

Contact/ Questions	Support Organization Statistics Canada Title of person in support role: Name: SASD Client Services Phone: 613-951-5979 E-mail: sasd-dssea@statcan.gc.ca
Web site	http://www12.statcan.ca/english/census06/index.cfm

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Below are the questions from the 2006 Census. For previous years refer to: Social and Aboriginal Statistics Division. How Statistics Canada Identifies Aboriginal Peoples. Ottawa: Statistics Canada 2007. Catalogue No.: 12-592-XIE. For the 2011 National Household Survey questions refer to: http://www12.statcan.gc.ca/NHS-ENM/ref/Questionnaires/2011NHS-ENM-eng.cfm. Aboriginal ancestry concept: Ethnic origin or ancestry refers to the ethnic or cultural origin of a person's ancestors, an ancestor being usually more distant than a grandparent. In the census, if a person reports at least one Aboriginal ancestry response, the person is counted in the Aboriginal ancestry population. Aboriginal identity concept: Three questions can be used to define the concept of Aboriginal identity, which forms the core of the data included in the January 15, 2008 Aboriginal census release: Aboriginal Identity (Question 18), Indian Band/First Nation Member (Question 20), and Registered Indian Status (Question 21). The identical questions were asked in 2006, 2001 and 1996 providing comparable data for three census years. Comparing Aboriginal census data over time: Any comparison of Aboriginal data across census years must adjust for incompletely enumerated reserves and settlements. Some Indian reserves and settlements did not participate in the census as enumeration was not permitted, or it was interrupted before completion. In 2006, there were 22 incompletely enumerated reserves, down from 30 in 2001 and 77 in 1996.  **17** What were the ethnic or cultural origins of this person's **ancestors**? *An ancestor is usually more distant than a grandparent.* *For example, Canadian, English, French, Chinese, Italian, German, Scottish, East Indian, Irish, Cree, Mi'kmaq (Micmac), Métis, Inuit (Eskimo), Ukrainian, Dutch, Filipino, Polish, Portuguese, Jewish, Greek, Jamaican, Vietnamese, Lebanese, Chilean, Salvadorean, Somali, etc.* *Specify as many origins as applicable using capital letters.* ☐☐☐☐☐☐☐☐☐☐☐ ☐☐☐☐☐☐☐☐☐☐☐ ☐☐☐☐☐☐☐☐☐☐☐ ☐☐☐☐☐☐☐☐☐☐☐ FOR INFORM **18** Is this person an Aboriginal person, that is, North American Indian, Métis or Inuit (Eskimo)? *If "Yes", mark "⊗" the circle(s) that best describe(s) this person now.* ○ No → **Continue with the next question** ○ Yes, North American Indian ○ Yes, Métis ○ Yes, Inuit (Eskimo) **Go to Question 20**

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question (cont.,)	 20 Is this person a member of an Indian Band / First Nation? ○ No ○ Yes, member of an Indian Band / First Nation *Specify Indian Band / First Nation (for example, Musqueam)* 21 Is this person a Treaty Indian or a Registered Indian as defined by the *Indian Act* of Canada? ○ No ○ Yes, Treaty Indian or Registered Indian Please, attach a blank electronic or hard copy of the questionnaire/data entry form that includes this question ☒ copy attached
Question Design	Reason why the above question and/or identifier was chosen: The content and flow of questions used in the Census are designed to describe and capture fluid aspects of ethno-cultural identification while maximizing response rate, maximizing the yield of valid and usable information and respecting the need to differentiate between First Nations, Inuit and Métis.
	Ethno-cultural identity question(s) has been tested Yes Test report re question design is available Yes Name/citation for test report: While the core content of the census has remained relatively stable since 1971, Statistics Canada has continued to modify census questions in order to remain responsive to emerging data needs and to ensure that the questions remain relevant to the demands of data users. 1. Social and Aboriginal Statistics Division. Report on Regional Discussions on Aboriginal Identification Questions. Ottawa: Statistics Canada 2008. Catalogue No.:89-629-X 2. Parent M, Lathe H. Testing for the 2011 Census of Canada. Statistics Canada Symposium 2008: Data Collection: Challenges, Achievements and New Directions. Ottawa: Statistics Canada 2009. Catalogue No.: 92-140-XWE 3. Social and Aboriginal Statistics Division. Aboriginal Peoples Technical Report, 2006 Census, Second Edition. Ottawa: Statistics Canada 2010. Catalogue No.: 92-569-X 4. Marketing Division. 2006 Census Content Consultation Report. Ottawa: Statistics Canada 2004. Catalogue No.:92-130-XIE
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Yes, If yes, barriers/gaps that have been addressed: To maximize response rate and validity, the Census long form was translated into 18 Aboriginal languages and interpreters were hired. In terms of mode of collection, Canada Post delivered a census questionnaire to about 70% of households, with the remaining 30% receiving their questionnaire from an enumerator. Householders were asked to complete the questionnaire for themselves and for members of their household and return it either online or in the postage paid yellow envelope. About 2% of households were enumerated using the canvasser method. An enumerator visited a household and completed a questionnaire for the household by a personal interview. This method was normally used in remote and northern areas of the country and on most Indian reserves. It was also used in large urban downtown areas where residents are transient.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

The resulting information, which is not available elsewhere, can be used to answer a wide range of questions of importance to First Nations, Inuit and Métis peoples. The size, coverage, and repetition of the Census/National Household Survey give it advantages over other data sources. The large sample size enables statistically stable estimates to be made for subgroups of the population. The inclusion of respondents from all provinces and territories allow geographic comparisons to be made across the country. Furthermore, the census includes some typically under-represented groups, such as urban Aboriginal people, non-status First Nations, off-reserve First Nations, and Métis. Another advantage of the Census approach is the comparability of the measure historically, since questions have remained relatively consistent over time.

This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated	Yes
Test /pilot/ evaluation report is available	Yes

Title/ citation for report: See references under Question Design

1. Hamel M, Hamilton G, Gilmour G. Changes in the Management of Data Collection Operations for the Canadian Census in 2011. Statistics Canada Symposium 2008: Data Collection, Challenges, Achievements and New Directions. Ottawa: Statistics Canada 2009. Catalogue No.:11-522-X

Data Linkage

Potential, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Answer 1.

1. Person-specific, longitudinal linkage to other databases is possible
2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible
3. Record linkage within the database is possible
4. No record linkage is possible, either within the database or to other databases

Data Quality

Documented Guidelines for asking and recording ethno-cultural identity are available	Yes
Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Yes
Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Yes
A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Yes

Data quality indicators that are used: Statistics Canada defines data quality as a degree or level of confidence that the data are "fit for use", relating to relevance, accuracy, timeliness, accessibility, interpretability and coherence. Indicators of data quality range from sampling errors to non-sampling errors, and include coverage, response rate, response error and processing errors, among others.

1. Social and Aboriginal Statistics Division. Aboriginal Peoples Technical Report, 2006 Census, Second Edition. Ottawa: Statistics Canada 2010. Catalogue No.: 92-569-X
2. Parent M, Lathe H. Testing for the 2011 Census of Canada. Statistics Canada Symposium 2008: Data Collection: Challenges, Achievements and New Directions. Ottawa: Statistics Canada 2009. Catalogue No.: 92-140-XWE

Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Yes

Title/citation for test/pilot/quality evaluation report: See references under Question Design

The Census and its Aboriginal identifiers are continually reviewed. The interpretation, usability as well as limitations of the data are well-documented. For further information, see citations below.

1. Social and Aboriginal Statistics Division. How Statistics Canada Identifies Aboriginal Peoples. Ottawa: Statistics Canada 2007. Catalogue No.: 12-592-XIE.
2. Guimond E. Fuzzy definitions and population explosion: changing identities of Aboriginal groups in Canada. Not strangers in these parts: urban Aboriginal peoples Ottawa (ON): Policy Research Initiative. 2003:35-49.
3. Guimond E. Ethnic mobility and the demographic growth of Canada's aboriginal populations from 1986 to 1996. Current Demographic Trends. 1999:190-1.

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers No
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Yes Barriers - if any – to ongoing collection of ethno-cultural identifiers: No. Refer to the questions and answers for the 2011 Census and National household surveys: http://census2011.gc.ca/ http://nhs.statcan.gc.ca/nhs-enm_r000-eng.htm

III. DATA ACCESS

Privacy Constraints	All personal information created, held or collected by Statistics Canada is protected by the Privacy Act and by the Statistics Act. The census collects data under the authority of more than 80 pieces of legislation, including the Canadian Charter of Rights and Freedoms, the Official Languages Act, and the Immigration Act. Census content must go through a rigorous consultation, testing, review and approval process to ensure every question responds to important information requirements that cannot be met through other means.
	A Privacy Impact Assessment has been done for this database Yes
	Information has been used for secondary purposes Yes If yes, examples of secondary data use: Numerous researchers, policy makers and other stakeholders use census data.
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Yes An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☒ Designer (e.g. of question) ☒ Collector of data ☐ Custodian ☒ Analyst ☐ User for decisions
	Ethno-cultural identifying questions were created and refined based on consultations with members of First Nations, Inuit and Métis groups. Refer to: 1. Social and Aboriginal Statistics Division. Report on Regional Discussions on Aboriginal Identification Questions. Ottawa: Statistics Canada 2008. Catalogue No.:89-629-X To facilitate communication between Statistics Canada and stakeholder communities, Statistics Canada has Aboriginal Liaison Program Advisors across the country. Aboriginal interviewers were hired wherever possible to administer the census questionnaire to those living in Aboriginal communities. Aboriginal organizations have conducted analysis using data from the 2006 Census.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Not Applicable

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Tjepkema M, Wilkins R, Senécal S, Guimond E, Penney C. Mortality of Métis and Registered Indian adults in Canada: an 11-year follow-up study. Health Reports 2009;20(4):31-51. 2. Statistics Canada produces reports on the range of topics covered by the census. For Aboriginal Specific reports see: http://www12.statcan.ca/census-recensement/2006/rt-td/ap-pa-eng.cfm
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Yes Examples of evidence-informed decisions: Information gained from the census informs countless decisions not only at various levels of government (i.e. federal, provincial/territorial and municipal) but also within independent businesses and organizations. See the 2006 2B Census Guide at the following link for more information: http://www12.statcan.gc.ca/census-recensement/2006/ref/pdf/3901_D15_T1_V1-eng.pdf
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Yes Statistics Canada works with national Aboriginal organizations to understand and fill data needs. Aboriginal Liaison Program Advisors work with other Aboriginal organizations and communities to fill data needs and build statistical capacity. Public Use Microdata Files (PUMFs) are freely available to the public. The PUMF contains data based on a sub-sample (i.e. <5%) of the population enumerated in the census and provides information on the demographic, social and economic characteristics of the Canadian population. This microdata file allows users to group and manipulate the data to suit their own requirements. Thus, it is a powerful research tool. To ensure the anonymity of respondents, geographic identifiers are in most cases restricted to the provinces/territories and large metropolitan areas. Two programs exist to offer researchers access to Statistics Canada data products. The Data Liberation Initiative (DLI) provides access to Statistics Canada's standard products, databases, public-use microdata and geographical files to post-secondary academic staff and students. The Research Data Centre (RDC) program provides secure access to detailed microdata for researchers with accepted proposals, after peer review by the Social Science and Humanities Council and provision of Statistics Canada deemed employee status. The DLI and RDC programs are run out of data centres located at universities and other accredited institutions across Canada. Statistics Canada has a wealth of publicly available reference materials on the census, collection methods, and quality of data, as well as a team of qualified analysts who can provide training and resources pertaining to the census on a cost-recovery basis.
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Statistics Canada is a national resource to federal, provincial/territorial and other jurisdictions on the topic of ethno-cultural identification, based on its long history of experience and expertise in developing and administering surveys and analyzing and interpreting the resulting information. While recognizing that ethno-cultural identification is fluid at any point in time, and subject to change over time, the approach taken in the Census is often the starting point for jurisdictions wishing to develop their own survey tools.
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: The questions used to identify First Nations, Inuit and Métis on the census capture multiple dimensions of Aboriginal ethno-cultural identification i.e. Status/Treaty, On/Off-reserve, Ancestry/Identity. Accordingly, this identifier is "high resolution" compared to a simpler Aboriginal identifier. The thorough and repeated evaluation of the questions used and their implications have yielded a significant literature about the strengths and weaknesses of these particular identifiers, which might reduce the necessity or depth of analysis and testing required by other organizations wishing to use similar questions. Furthermore, census data could be used to certify other data sources. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: The five questions used to identify First Nation, Inuit and Métis people on the Census have a relatively larger burden on the interviewer and respondent than potentially simpler questions.

IV. DATA USE & REPORTING

Additional Comments	Why census counts differ from Indian Register Counts: The number of Registered Indians recorded by Indian and Northern Affairs Canada's Indian Register differs from Statistics Canada's census counts of Registered Indians. This is because the two data sources do not count Registered Indians in the same way or for the same purpose. The Indian Register is an administrative database, while the census is a statistical survey. The census is a snapshot of the population on Census Day. It counts individuals at the place they consider to be their usual residence, where they have spent the majority of the past year, or, if they have no other usual place of residence, where they were on Census Day — May 16, 2006. For example, individuals who are affiliated with a specific Indian band on the Indian Registry may have a usual place of residence elsewhere compared with what is recorded in the register. The Indian Register includes all Registered Indians, including those living outside Canada and those in institutions. It is updated by registering events such as births, deaths, status changes, adoption, etc. In contrast, the census does not collect information about Registered Indian status from institutional residents or persons living outside Canada (other than those living on a military base or attached to a diplomatic mission, at sea or in port aboard merchant vessels under Canadian registry).

5.7.5 Longitudinal Health and Administrative Data Initiative

I. DATABASE – Longitudinal Health and Administrative Data Initiative	
Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☒ MB ☒ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NV ☐ Other Specify
Description	A partnership (cf. Data Sources below) that allows for linking provincial-territorial health administrative databases to existing Statistics Canada data to effectively answer important health policy questions in a cost-efficient manner. LHAD is not a database. Rather, it is a process or mechanism that enables high quality, timely and cost-efficient linkage of exiting databases for the purpose of statistical research. The participating databases remain with their own custodians. The LHAD Initiative allows linkage through the creation of a Key Registry.
Custodian	Statistics Canada is the operational arm of the LHAD Initiative; see also Data Sources (below)
	Mandate of Custodian: The Statistics Act gives Statistics Canada the mandate to collect, compile, analyse, abstract and publish statistical information relating to the commercial, industrial, financial, social, economic and general activities and condition of the Canadian people.
Purpose	To address important information gaps by ensuring that key administrative data, such as those routinely collected through the health system, can be used to undertake pan-Canadian research to improve the understanding of relationships among risk factors, socio-economic characteristics, health outcomes and health utilization. Data collected by Statistics Canada are used for statistical, research and analytical purposes, but not for administrative purposes.
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☒ Research ☒ population ☐ clinical ☒ program/service ☒ public policy
	☐ Service Delivery ☐ enrolment/ membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☒ Database includes demographic data
	☒ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☒ First Nation/ North American Indian ☒ Status (registered, treaty) ☒ Non-status ☒ On-reserve ☒ Off-reserve ☐ Band name or number
	☒ Inuit/ Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☒ Métis ☐ On Métis register ☐ Other Specify
	☒ Aboriginal ☐ Other Specify
	LHAD itself is not a database; it would be more accurate to state that the Initiative allows for the linkage of data elements, such as ethno-cultural identifiers for research purposes. This could include identifiers on the census, or identifiers present in jurisdictional data sets.
Data Sources	1. Hospital Inpatient Discharge Data - DAD (CIHI); 2. Hospital Outpatient Data - NACRS (CIHI); 3. Prescription Drug Data from Provincial Drug Plans - NPDUIS (CIHI); 4. Population Registry Data from health insurance plan population registries (to permit accurate record linkage; not available to researchers); 5. Births and Deaths Databases from provincial/ territorial vital statistics registries (Statistics Canada); 6. Canadian Cancer Registry - CCR (Statistics Canada); 7. Population Health Surveys - CCHS & NPHS (Statistics Canada); 8. Canadian Health Measures Survey (Statistics Canada); 9. Taxation Data - Historic Summary Tax File & T1 Family File (Canada Revenue Agency); 10. Census of Population and National Household Survey - 1991 - 2011 (Statistics Canada); 11. Longitudinal Immigration Database (Statistics Canada).

I. DATABASE – Longitudinal Health and Administrative Data Initiative

	The LHAD Initiative is a partnership among provincial/territorial ministries of health, Statistics Canada, Canadian Institute for Health Information, Canadian Council of Cancer Registries and Vital Statistics Council for Canada to complement important record linkage research already being done within individual P/Ts, learn from comparisons among jurisdictions, and facilitate larger scale studies for less common types of events and conditions.
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): 1992/93 Month/year of latest available ethno-cultural identifiers: 2006
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☒ Regional (e.g. RHA/ LHIN) ☐ Local (e.g. facility) ☐ Other Specify
	Postal Code
Service Domain	☒ Acute Care ☒ Emergency Care ☐ Complex Continuing Care ☐ Rehabilitation ☒ Mental Health/ Addictions ☐ Palliative Care ☐ Long Term Care ☐ Home & Community Care ☐ Primary Care ☒ Drugs ☒ Cancer ☐ Diabetes ☐ Renal Dialysis ☐ Immunization ☐ Communicable Disease
Users	Primary users of this database - Provincial/territorial policy makers and population health researchers
	Database also used by users external to Custodian
Populations	Population groups included in this database – Canadians
Records	Total # of records in database: Depends on a particular linkage project and the associated files; qualified researchers could also link their own data files.
Contact/ Questions	Support Organization Statistics Canada Title of person in support role: Assistant Director, Health Statistics Name: Bob Kingsley Phone: 613-951-3760 E-mail: Bob.Kingsley@statcan.gc.ca
Web site	http://www.statcan.gc.ca/pub/82-622-x/2010004/intro-eng.htm

II. DATA DESIGN, COLLECTION/ LINKAGE, RECORDING & STORAGE

Method	This method for collecting/ linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Yes. If yes, barriers/ gaps that have been addressed: Overall, LHAD is an open data model that combines a common infrastructure of record linkage and privacy management with high flexibility of source files that can be linked for highly customized research. 1) LHAD is the first collaboration where personal health info from clinical databases routinely collected through the P/T health system - including ethno-cultural identifiers - can be linked to national data holdings to answer important research questions in (Aboriginal) population health. It provides a picture of the entire population is standardized, longitudinal, cost-effective and enables studies to be done that could not otherwise be performed. 2) LHAD does not require the new collection of personal health information directly from Canadians, including First Nations, Inuit and Métis peoples, as it utilizes data already in existence and routinely collected. This reduces cost associated with collecting and linking health data, as well as alleviates the burden of data collection on responders, administrators and researchers. LHAD also reduces the burden of data linkage on researchers. 3) LHAD utilizes a Key Registry for data linkage, which allows storing sensitive personal information separate from the data of the various LHAD databases. This significantly improves the quality and efficiency of database linkages, as well as strengthens management of data security. Since the information is used only for statistical, research and analytical purposes, no decision about individual persons can be based on the copy of their records held by Statistics Canada. As well, under the Access to Information Act, information protected by the confidentiality provisions of the Statistics Act is subject to a mandatory exemption from disclosure. 4) LHAD combines the resources and expertise of (i) provincial/territorial health data and research centres with expertise in the development of provincial health data holdings and their application to research, (ii) CIHI, Canada's national health data organization with unique capabilities in setting data standards to promote

II. DATA DESIGN, COLLECTION/ LINKAGE, RECORDING & STORAGE

	compatibility between provincial health admin databases, and Canada's national statistics organization, with state-of-the-art protocols for the protection of privacy, confidentiality and security, while contributing to the highest standard of data management and analysis. 5) Record linkage proposals must satisfy a rigorous review/ approval process that is open to external researchers, including qualified First Nations, Inuit and/or Métis research groups. If a record linkage proposal is approved, external researchers must be deemed to be employed under the Statistics Act and would carry out their work in one of the university-based Research Data Centres where a Statistics Canada employee can coordinate data access and screen outputs to ensure they comply with strict confidentiality and privacy requirements.
Data Quality	Provincial/territorial health admin data custodians, CIHI and Statistics Canada all have their own quality assurance procedures in place. LHAD enables the combination of the most detailed information available on health care utilization and outcomes (admin health databases) with the best info available on the demographic, socio-economic and health characteristics of Canadians (Statistics Canada data holdings).
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Yes A formal cost recovery study has not been done for LHAD. Nevertheless, a stand-alone Statistics Canada record study for a mid-size cohort costs $150,000-$200,000. In addition, ad hoc record linkage studies have to go through their own privacy clearance process - which can be very resource-intensive and time-consuming. As opposed to this, the fee for creating (most) LHAD data files is $10,000 - $30,000. And the LHAD Initiative creates considerable time and resource efficiencies as every project follows the same procedure, including privacy clearance through the institutionalized Privacy Impact Assessment (PIA).

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database: Statistics Canada is subject to the Statistics Act, restricting the use of the data to statistical purposes only. A formal LHAD governance structure was developed in close consultation with the provinces, taking into account the confidentiality and privacy legislative environment within which research is to be conducted. These arrangements are documented in bilateral Memoranda of Understanding (MOU) that are signed by each participating jurisdiction, and define the terms and conditions under which research may be undertaken using the LHAD environment. Any requests received for information provided in confidence by the provinces/territories would be refused based on the appropriate exemption under the Access to Information Act. A comprehensive Privacy Impact Assessment (PIA) examining the potential privacy, confidentiality and security risks associated with the LHAD Initiative has been completed and approved by the Chief Statistician of Canada and later provided to the Office of the Federal Privacy Commissioner (OPC) where it received a positive response.
	A Privacy Impact Assessment has been done for this database Yes
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/ or Métis groups were consulted on the purpose and/or design of the database Not Applicable An MOU or formal agreement governing development and/or use of the database is in place Not Applicable First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	As a national statistical agency under the Statistics Act, Statistics Canada shares data - under strict conditions to safeguard privacy, confidentiality and security - with qualified researchers. By law, the agency cannot give away data. Neither can it engage in activities that are of a political nature, and could undermine its position as a neutral and trustworthy statistical agency.
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Not Applicable Inuit Land Claims research protocols Not Applicable Métis requirements Not Applicable

IV. DATA USE & REPORTING	
Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Yes Examples of analyses, reports, publications: 1. Study linking hospitalization data with census data to explore health care utilization patterns among immigrants and the aboriginal population. For the first time in Canada, researchers will be able to analyse in a methodologically consistent and cross-jurisdictionally comparable way, variations in hospital usage for specific sub-populations, and at the same time, incorporate a wide range of socio-economic variables (e.g. income, education, employment, housing etc.) that bring invaluable contextual information and analytical power. 2. Preliminary analysis of population aging will establish baseline information that will ultimately be used to link census and mortality data to explore end of life care and outcomes (both inside and outside of hospital), to better explore questions surrounding effectiveness and sustainability.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. Recommendation for future research to examine broader, more culturally relevant predictors of health among Aboriginal people.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One As of September 8, 2011, two jurisdictions (Ontario and Manitoba) have signed on as partners in LHAD. Two others have declined participation, and the balance of provinces/ territories have not indicated a formal position. Given that the development of LHAD has taken five years, with considerable investment from Statistics Canada, and in view of increased budget austerity going forward, the future of LHAD is uncertain. Thoughts/ advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Federal and Provincial/ Territorial ministers of health are in discussion to understand barriers to adoption of the LHAD Initiative. Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Provinces have articulated privacy concerns around data management - despite approval of the PIA by the Chief Statistician of Canada, and support from the Federal Privacy Commissioner. In response to these concerns, Statistics Canada offers expertise and resource to interested P/Ts to address privacy issues.
Additional Comments	Further to the descriptions under "Method" point 5, and "Privacy Constraints" above, the following provides further detail that may be helpful to potential users of the LHAD infrastructure: Re the protection of proprietary data that are not part of the Statistics Canada data holdings, i.e. data that were not collected by the agency: Custodians/ Data Owners who have their own data set can bring this data set into the LHAD environment WITHOUT losing control over protection of their data. In other words, neither that data, nor the data set resulting from linking it to other data files can be shared with third parties. A hypothetical example of this would be a database containing records of employees of a mining company that could be linked to LHAD holdings to better understand occupational-environmental risks associated with exposure in different job categories. Both the employee records, as well as the linked data cannot be shared by Statistics Canada with third parties. So, First Nations, Inuit and/or Métis groups who have their own data sets would be protected under the LHAD infrastructure in terms of ownership, control, access and possession of the data sets they have collected themselves. Re the availability of the LHAD infrastructure to potential users: The corollary of the above is that any studies/ linkage projects done under the LHAD infrastructure have to serve a public good. As a publicly funded agency, Statistics Canada cannot subsidize private research. It will work with external researchers who qualify on a (highly cost-efficient) cost-recovery basis. To qualify, external researchers must satisfy a prescribed review process that includes a) a description of the broader "public good" of the proposed linkage, showing how the public interest is served by the project, and why a record linkage is the only practical means to achieve this public benefit; b) details regarding the outputs of the linked file, and the dissemination plans for the resultant findings. A full description of the application and review process can be found in "Longitudinal Health and Administrative Data (LHAD) Initiative - Overview of the Partnership", Statistics Canada, Health Statistics Division, June 2011, pages 5 -7.

EXHIBIT A

DATA COLLECTION FORM - DCF V2.0-S FOR SINGLE-SOURCE DATABASES

CANADIAN PARTNERSHIP AGAINST CANCER

Enviro scan and analysis of existing patient identification systems for First Nations, Inuit, and Métis peoples

DATA COLLECTION FORM
VERSION 2.0-S
SEPTEMBER 1, 2011

The Bridge Consulting Group

The Canadian Partnership Against Cancer has asked The Bridge Consulting Group to conduct an Environmental Scan and Analysis of Existing Patient Identification Systems for First Nations, Inuit and Métis peoples. This project is part of the Partnership's First Nations, Inuit, and Métis Action Plan on Cancer Control (June 2011).

The goal of the project is to identify existing systems of patient identification specific to First Nations, Inuit and Métis ethnicity, and to analyze barriers to developing common standards for data collection, access and reporting (as a means to improve patient navigation). The Partnership's 2011/12 action plan includes a commitment to document existing systems of ethno-cultural patient identification for First Nations, Inuit, and Métis populations, and to analyze and identify leading practices.

The attached Data Collection Form has been designed to capture information about electronic health databases that include ethno-cultural identifiers for First Nations, Inuit, and/or Métis populations. This information will assist us in i) developing profiles of selected databases, and ii) analyzing barriers to developing acceptable systems of ethno-cultural identification, and of standards for data collection, access and analysis.

The longer term impact the Partnership pursues is to improve the ability to collect baseline information (i.e. incidence, care patterns and outcomes), and thus target services to areas of most need, leading to improved cancer care for and with First Nations, Inuit and Métis peoples.

For questions or information about this form or the project, please contact

Drs. Henneke Cats, Engagement Lead

The Bridge Consulting Group

Telephone: 416-226-2251 E-mail: Henneke@yourbridge.com

Definitions of key terminology:

Demographic data:	e.g. name, address, date of birth, gender
Ethno-cultural data:	e.g. Aboriginal, First Nations, Inuit, and/or Métis identifiers
Enrolment:	e.g. enrolment in health insurance, or in health care program
Membership:	e.g. band membership/First Nation affiliation, Métis group membership
OCAP:	First Nations principles for Ownership, Control, Access, and Possession of health data
Support Organization:	typically, the database custodian provides support for questions regarding the database

Before entering data into the Data Collection Form, please do a Save As and rename the document by including the date of completion, your first initial and last name, i.e., DCFv2.0-M_DB_**2011-07-16_JSmith**.doc.

There are three options for entering data in the Data Collection Form:

- Use the TAB key to tab through each section to enter the information, or
- Use the up/down arrows on the keyboard to move to each section to enter the information, or
- Select each field using the mouse cursor to enter the information.

Name of interviewee/key informant:	
Title:	
Organization:	
Phone number:	
E-mail:	
Title/citation for key information document(s):	
Interviewer:	
Date of interview, or completion of data form:	

I. DATABASE – Actual name given by Custodian

Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify
Description	Summary of description of the database
Custodian	Name of organization that holds database
	Mandate of Custodian: Please specify
Purpose	Principal decision(s) or activities that the information is intended for (in your words)
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify
	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability
	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy
	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☐ Database includes demographic data
	☐ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers
	☐ First Nation/North American Indian ☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number
	☐ Inuit/Inuk ☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut
	☐ Métis ☐ On Métis register ☐ Other Specify
	☐ Aboriginal ☐ Other Specify
	Comments (Optional)
Status & Update	Database status Select One
	Database update frequency Select One Frequency of Updates:
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98): Month/year of latest available ethno-cultural identifiers:
Level of Detail	1. Select One 2. If Individual Record was selected: Select One 3. If Not identifiable was selected: Select One
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Specify
	Select One
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer ☐ Emergency Care ☐ Long Term Care ☐ Diabetes ☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis ☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease
Users	Primary users of this database - A short list of key users
	Select One
Populations	Population groups included in this database – A short list of key populations
	Population Coverage - % of population targeted by the database that has been captured: Example: this provincial cancer registry captures around x% of all

I. DATABASE – Actual name given by Custodian

	incident cancer cases	
	Alternatively, sample with weights? Select One . If yes, sample size % of population	
Records	Total # of records in database:	Annual number of records collected/updated:
Contact/ Questions	Support Organization Title of person in support role: Name: Phone: E-mail:	
Web site	URL for further information	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethno-cultural Identity Question	Verbatim reproduction of the ethno-cultural identity question(s): Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question ☐ copy attached	
Question Design	Reason why the above question and/or identifier was chosen: Please describe	
	Ethno-cultural identity question(s) has been tested Select One Test report re question design is available Select One Name/citation for test report:	
Method	This method for collecting, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Select One , If yes, barriers/gaps that have been addressed: Please describe	
	This method for collecting ethno-cultural identifiers has been tested, validated, and/or formally evaluated Select One Test /pilot/ evaluation report is available Select One Title/ citation for report:	
Data Linkage	<u>Potential</u>, i.e. “technical feasibility”, for data linkage (check highest level possible, with 1 being highest): Select One 1. Person-specific, longitudinal linkage to other databases is possible 2. Aggregate level linkage (e.g. using three digit postal code) to other databases possible 3. Record linkage within the database is possible 4. No record linkage is possible, either within the database or to other databases	
Data Quality	Documented Guidelines for asking and recording ethno-cultural identity are available	Select One
	Staff Training Program for these guidelines is in place (e.g. to ensure questions are asked consistently and in a culturally appropriate way)	Select One
	Awareness/education materials for patients/clients are available (e.g. to explain why patients/clients are asked to self-identify)	Select One
	A systematic approach to evaluating the quality of ethno-cultural identification data is in place	Select One
	Data quality indicators that are used: Please specify	
	Formal evaluation of the validity, usability and completeness of the ethno-cultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	

II. DATA DESIGN, COLLECTION, RECORDING & STORAGE

	Comments on quality (optional)
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)
Capacity	The custodian plans to keep collecting the ethno-cultural identifiers Select One Barriers - if any – to ongoing collection of ethno-cultural identifiers:

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database
	A Privacy Impact Assessment has been done for this database Select One
	Information has been used for secondary purposes Select One If yes, examples of secondary data use:
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Select One An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would Support the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment Limit the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

EXHIBIT B

DATA COLLECTION FORM - DCF V2.0-M FOR MULTI-SOURCE DATABASES

CANADIAN PARTNERSHIP AGAINST CANCER

Enviro scan and analysis of existing patient identification systems for First Nations, Inuit, and Métis peoples

DATA COLLECTION FORM

VERSION 2.0-M

SEPTEMBER 1, 2011

The Canadian Partnership Against Cancer has asked The Bridge Consulting Group to conduct an Environmental Scan and Analysis of Existing Patient Identification Systems for First Nations, Inuit and Métis peoples. This project is part of the Partnership's First Nations, Inuit, and Métis Action Plan on Cancer Control (June 2011).

The goal of the project is to identify existing systems of patient identification specific to First Nations, Inuit and Métis ethnicity, and to analyze barriers to developing common standards for data collection, access and reporting (as a means to improve patient navigation). The Partnership's 2011/12 action plan includes a commitment to document existing systems of ethno-cultural patient identification for First Nations, Inuit, and Métis populations, and to analyze and identify leading practices.

The attached Data Collection Form has been designed to capture information about electronic health databases that include ethno-cultural identifiers for First Nations, Inuit, and/or Métis populations. This information will assist us in i) developing profiles of selected databases, and ii) analyzing barriers to developing acceptable systems of ethno-cultural identification, and of standards for data collection, access and analysis.

The longer term impact the Partnership pursues is to improve the ability to collect baseline information (i.e. incidence, care patterns and outcomes), and thus target services to areas of most need, leading to improved cancer care for and with First Nations, Inuit and Métis peoples.

For questions or information about this form or the project, please contact

Drs. Henneke Cats, Engagement Lead

The Bridge Consulting Group

Telephone: 416-226-2251 E-mail: Henneke@yourbridge.com

Definitions of key terminology:

Demographic data:	e.g. name, address, date of birth, gender
Ethno-cultural data:	e.g. Aboriginal, First Nations, Inuit, and/or Métis identifiers
Enrolment:	e.g. enrolment in health insurance, or in health care program
Membership:	e.g. band membership/First Nation affiliation, Métis group membership
OCAP:	First Nations principles for Ownership, Control, Access, and Possession of health data
Support Organization:	typically, the database custodian provides support for questions regarding the database

Before entering data into the Data Collection Form, please do a Save As and rename the document by including the date of completion, your first initial and last name, i.e., DCFv2.0-M_LHAD_2011-09-16_JSmith.doc.

There are three options for entering data in the Data Collection Form:

- Use the TAB key to tab through each section to enter the information, or
- Use the up/down arrows on the keyboard to move to each section to enter the information, or
- Select each field using the mouse cursor to enter the information.

Name of interviewee/key informant:	
Title:	
Organization:	
Phone number:	
E-mail:	
Title/citation for key information document(s):	
Interviewer:	
Date of interview, or completion of data form:	

I. DATABASE – Actual name given by Custodian

Geography	☐ Canada ☐ BC ☐ AB ☐ SK ☐ MB ☐ ON ☐ QC ☐ NB ☐ NS ☐ PE ☐ NL ☐ YT ☐ NT ☐ NU ☐ Other Specify			
Description	Summary of description of the database			
Custodian	Name of organization that holds database			
	Mandate of Custodian: Please specify			
Purpose	Principal decision(s) or activities that the information is intended for (in your words)			
	☐ Public Health & Surveillance ☐ screening ☐ immunization ☐ communicable disease ☐ other Specify	☐ Operating a Health Organization or System ☐ funding & reimbursement ☐ transactions, e.g. drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☐ Research ☐ population ☐ clinical ☐ program/service ☐ public policy	☐ Service Delivery ☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation
Demographics	☐ Database includes demographic data	☐ Database includes Aboriginal, First Nations, Inuit and/or Métis ethno-cultural identifiers		
	☐ First Nation/North American Indian	☐ Inuit/Inuk	☐ Métis	☐ Aboriginal
	☐ Status (registered, treaty) ☐ Non-status ☐ On-reserve ☐ Off-reserve ☐ Band name or number	☐ Inuvialuit ☐ Nunavut ☐ Nunavik ☐ Nunatsiavut	☐ On Métis register ☐ Other Specify	☐ Other Specify
Data Sources	1. Name the source files of this database 2. etc.			
	Comments (Optional)			
Availability	Month/year of earliest available ethno-cultural identifiers (e.g. FEB-98):	Month/year of latest available ethno-cultural identifiers:		
Geographic Codes	Geographic level to which ethno-cultural FNIM identifiers can be obtained: ☐ National ☐ Province/Territory ☐ Regional (e.g. RHA/LHIN) ☐ Local (e.g. facility) ☐ Other Specify			
	Select One			
Service Domain	☐ Acute Care ☐ Palliative Care ☐ Cancer	☐ Emergency Care ☐ Long Term Care ☐ Diabetes	☐ Complex Continuing Care ☐ Home & Community Care ☐ Renal Dialysis	☐ Rehabilitation ☐ Primary Care ☐ Immunization ☐ Mental Health/Addictions ☐ Drugs ☐ Communicable Disease

I. DATABASE – Actual name given by Custodian

Users	Primary users of this database - A short list of key users
	Select One
Populations	Population groups included in this database – A short list of key populations
Records	Total number of records in database:
Contact/Questions	Support Organization Title of person in support role: Name: Phone: E-mail:
Web site	URL for further information

II. DATA DESIGN, COLLECTION/LINKAGE, RECORDING & STORAGE

Method	This method for collecting/linking, accessing and/or reporting ethno-cultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification: Select One . If yes, barriers/gaps that have been addressed: Please describe
Data Quality	Comments on quality (optional)
Data Cost	This approach replaces a more costly way to collect ethno-cultural identifiers Select One Comments on cost (optional)

III. DATA ACCESS

Privacy Constraints	Privacy constraints (e.g. legislation, protocols, agreements) that govern access to this database
	A Privacy Impact Assessment has been done for this database Select One
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database Select One An MOU or formal agreement governing development and/or use of the database is in place Select One First Nation, Inuit and/or Métis people have taken on role(s) in this ethno-cultural identification project as ☐ Designer (e.g. of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions
	Comments on the nature and/or outcome of engagement (optional)
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows: First Nations OCAP principles Select One Inuit Land Claims research protocols Select One Métis requirements Select One

IV. DATA USE & REPORTING

Data Products	Analyses, reports, publications have been done using ethno-cultural identifiers in the database Select One Examples of analyses, reports, publications: 1. 2.
Evidence-informed Decisions	The ethno-cultural identifiers have informed practice, policy and/or research decisions Select One Examples of evidence-informed decisions: 1. 2.
Reporting	Information/analysis has been shared with ethno-cultural groups who have an interest in its collection and use Select One Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	Other jurisdictions plan to adapt or adopt this approach to ethno-cultural identification Select One Comments (optional)
	Thoughts/advice on factors that would <u>Support</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment <u>Limit</u> the re-application of this ethno-cultural identification approach to other jurisdictions: Please comment
Additional Comments	Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethno-cultural identifiers

EXHIBIT C

GLOSSARY OF TERMS

Demographic data:	e.g., name, address, date of birth, gender
Ethnocultural data:	e.g., Aboriginal, First Nations, Inuit, and/or Métis identifiers
Enrolment:	e.g., enrolment in health insurance, or in health care program
Membership:	e.g., band membership/First Nation affiliation, Métis group membership
OCAP:	First Nations principles for Ownership, Control, Access, and Possession of health data
Support Organization:	Typically, the database custodian provides support for questions regarding the database