

Internship Report

Aboriginal Population Data Indicators Pilot

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Juravinski Cancer Centre at Hamilton Health Sciences

699 Concession Street, Hamilton, ON



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Sunil Nair – B00492855

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And, I would like to especially thank Dr. Grace Paterson for her support and understanding all the way.

Executive Summary

The author undertook the “Aboriginal Population Data Indicators pilot Project” as an internship with the Cancer Informatics Unit (CIU) of Juravinski Cancer Centre (JCC) at Hamilton Health Sciences in Hamilton, Ontario, between June and August of 2009.

The Aboriginal Population Data Indicators Pilot Project was rolled out to develop and evaluate a data collection tool to identify Aboriginal status of Cancer patients visiting the two regional cancer center’s selected by Cancer Care Ontario (CCO). Hamilton and Thunder Bay areas were chosen because of the large Aboriginal populations in the respective LHIN’s.

The objective of the project is to gather quality cancer specific data on Aboriginal people and to use the data to extract knowledge that would aid in decision making and policy planning which in turn would improve the health status of the Aboriginal community.

Currently, no identification data is collected on Aboriginality. The potential benefits of the pilot project are:

- Demonstrate to Aboriginal providers, organizations and communities the value of collecting and analyzing data on Aboriginal health.
 - This information can assist in improving the health status of Aboriginal people and the quality of care they receive in Ontario. Furthermore, it will help the cancer centre to gain a better understanding of the cancer care needs of the Aboriginal populations served in their areas.
 - This information can also be used to see which groups are being under-serviced, for example if their cancers are being caught at later stages. This will give us the kind of information as to which groups may need to be targeted for better services; and
- To provide a template for developing other sources of data on Aboriginal health.

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1. Introduction

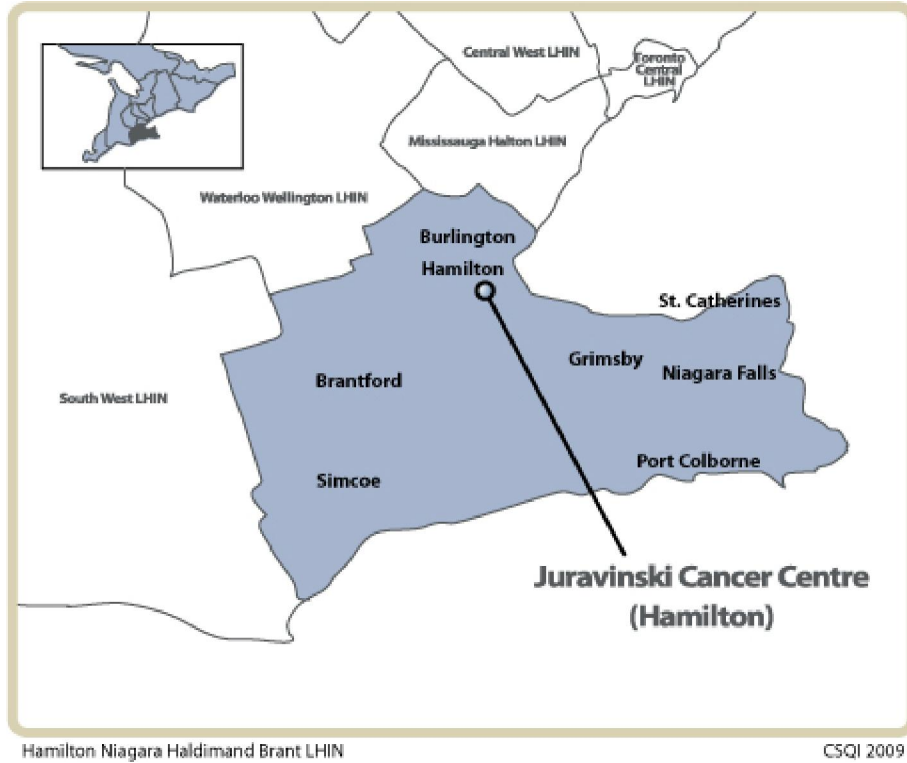
This 13-week Internship is undertaken in partial fulfilment of the Masters in Health Informatics Program at Dalhousie University, Nova Scotia. The work was performed at the Juravinski Cancer Centre (JCC) at the Hamilton Health Sciences (HHS) located in Hamilton, Ontario.

The objective of the Internship was to provide ‘real world’ experience of IT/IM operational environment within a Health Care Organization. The Intern was employed as a Project Coordinator by the Cancer Informatics Unit (CIU) division of JCC.

For the purpose of this Internship, the Intern focused on “The Aboriginal Population Data Indicators Pilot Project”.

1.1 Juravinski Cancer Centre at Hamilton Health Sciences (JCC)

JCC is a comprehensive regional cancer centre serving as a tertiary and quaternary facility in the Hamilton Niagara Haldimand Brant LHIN area providing cancer care and treatment to over 1.4 million people. Integrated with the Hamilton Health Sciences, JCC is a strategic partner of Cancer Care Ontario (CCO) and is a level one facility having academic (teaching and research) responsibilities. The JCC collaborates with six community hospitals in the region namely Brant Community Healthcare Alliance - Brantford, Hamilton Health Sciences - Hamilton, Joseph Brant Memorial Hospital – Burlington, Niagara Health System – Niagara, Norfolk General Hospital and St. Joseph’s Healthcare – Hamilton. [1]

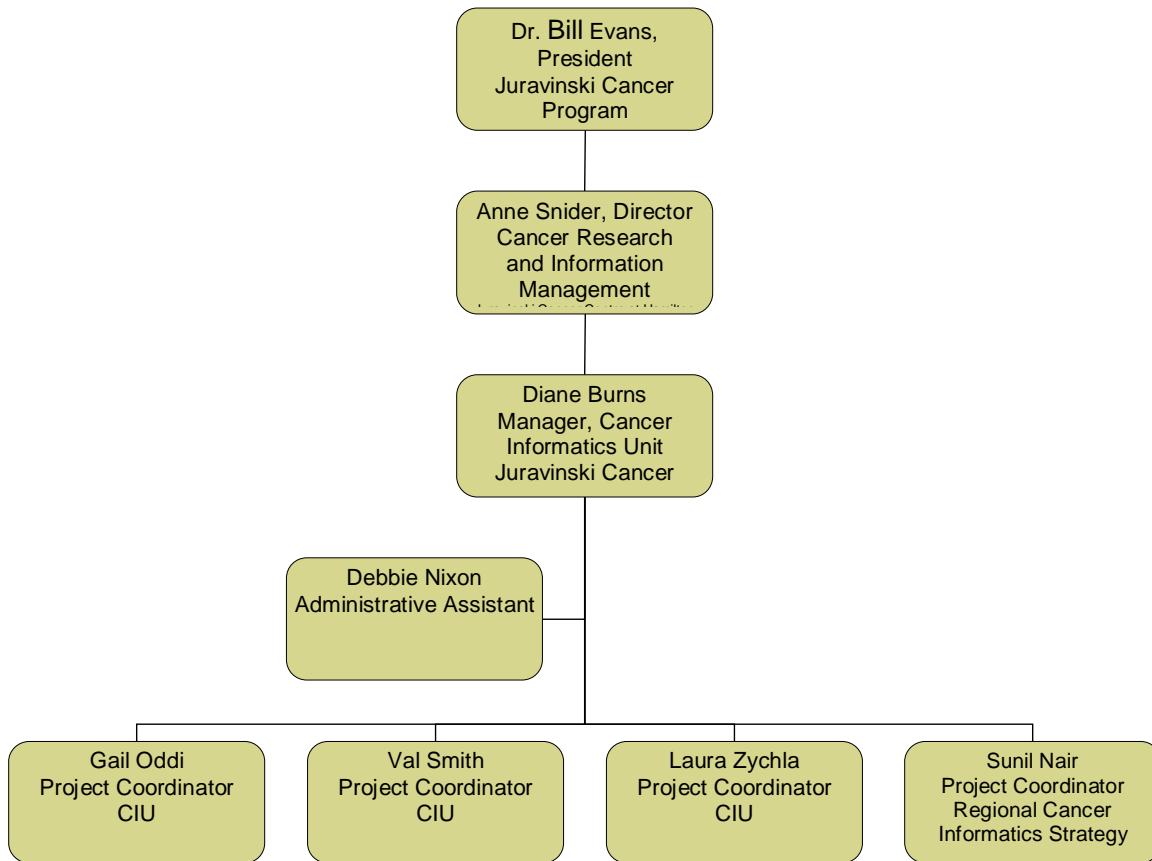


1.2 Cancer Informatics Unit (CIU)

The objectives of the CIU team are to provide data, planning and analytic functions to support decision making at all levels in the regional cancer program. Other responsibilities of CIU are to provide:

- process review, quality improvement and education in order to assist the decision makers optimize the use of data and clinical information systems and tools;
- leadership in the development of clinical information systems supporting the regional cancer program;
- ensure submission of timely, accurate, consistent, high quality data to Cancer Care Ontario, the Ontario Ministry of Health and Canadian Institute of Health Information. [2]

1.2.1 CIU Organizational Structure



2. Internship Role and Work Performed

The Internship was positioned within the Cancer Informatics unit of JCC to work in developing and implement decision tools designed to support decision making in the Integrated Cancer Program. The role involved managing designated projects undertaken by the CIU. Responsible for analysing and establishing processes, standards, techniques and procedures that helps in clinical decision making, business operations, quality improvement, system integration, development and implementation and data collection for designated projects.

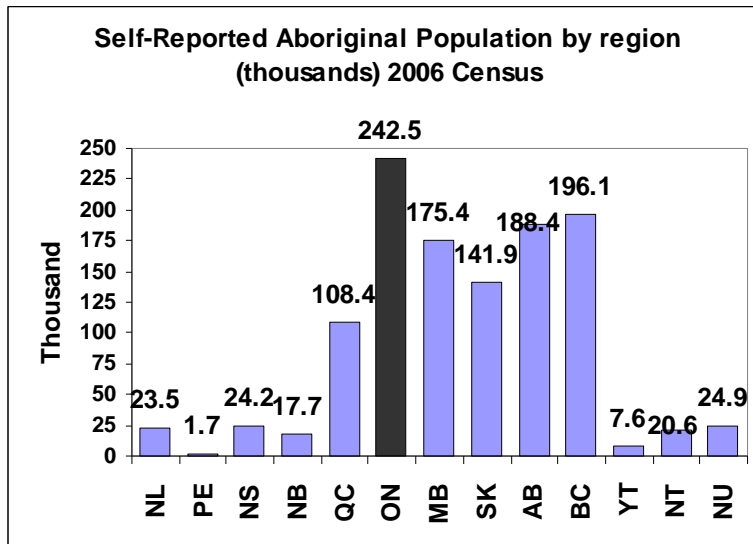
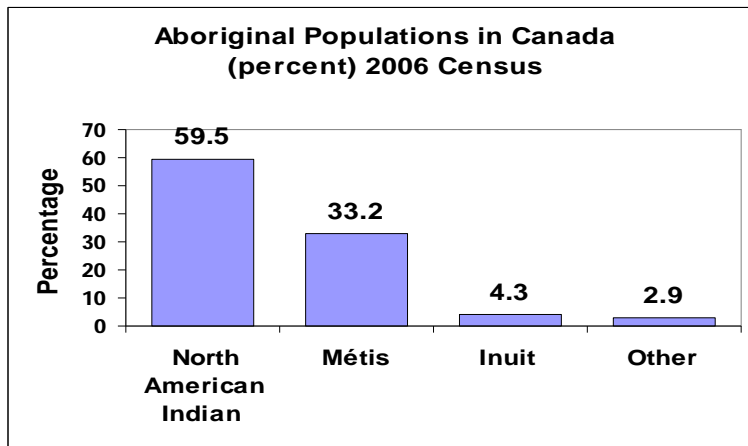
Duties:

- Assist the Cancer Informatics Unit Manager in developing Strategic Plans and Priorities for Cancer Informatics Unit initiatives;
- Work in conjunction with various committees or programs and carry out assigned project initiatives and recommend solutions to ensure practical and efficient business operations;
- Assist teams with the development and implementation of processes and systems for data collection, reporting, utilization, retrieval and analysis of clinical program and management information;
- Extract and analyze data related to budgets, resource utilization, quality of patient care, workload standards;
- Act as a resource to clinical areas in the identification of quality indicators to measure specific outcomes;
- Develop and maintain a productive working relationship with project team and key user groups; and
- Conduct business and process analysis.

3. Project Introduction

3.1 Aboriginal Population of Canada

In the last 10 years, the Aboriginal population in Canada has grown six times making the total number of people who identified themselves as First Nation, Metis and Inuit to cross the 1 Million mark. Among nations, Canada has the second highest number of Indigenous people with almost 50 % living in remote areas (Statistics Canada 2006 Census). The province of Ontario has more than 240,000 aboriginals where more than half live off the reserve.



Source: Statistics Canada. Aboriginal Peoples in Canada in 2006: Inuit, Metis and First Nations, 2006 Census. Ottawa, Statistics Canada, 2008.

2.2 Background

An effective Cancer Surveillance System must include continuous monitoring of cancer incidence rates and survival outcomes. Surveillance data is crucial in the development of strategies and initiatives that can successfully control the increasing burden of cancer in populations. Historically, Canada has always been a global leader in data collection and analysis by way of its provincial cancer registries and national databases. However, Information about cancer burden in the Canadian Aboriginal Populations was inadequate and inaccurate. The various data collection methodologies were found to have inherent problems, namely, the lack of staging and population specific data. The data collected was neither standardized nor interoperable; it could not be compared or evaluated for changes over time. This resulted in an inability to design treatment programs targeting the growing and diverse Aboriginal population. However, the data collected at the national, provincial and territorial levels indicated that there is a significant rise in the cancer incidence and mortality rates among the Aboriginal peoples of Canada. [3]

It can be assumed that the as the median age of the Aboriginal populations goes up the incidence of cancer would also show a dramatic increase. The above coupled with aggressive screening programs and better access to care could result in early cancer diagnosis which would subsequently amplify an increase in some cancers and in some regions. Because of early diagnosis and better treatment facilities survival would be better, this would mean more resources would be needed in palliative and supportive care areas. Therefore, the need to develop a highly effective cancer surveillance system is critical to prevent a severe impact on the health system. [4]

According to Information Specialist, Donatiello and Droese 2004, at the Center for State Health Policy, health care disparity is widespread among the ethnic populations of the world. Their comprehensive list of references indicate that differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions exists among specific population groups [5]

3.0 Cancer Surveillance Challenges

In 2003, under the leadership of Cancer Care Ontario, the "First Nations Cancer Research and Surveillance Priorities for Canada" workshop was organized. The main focus of the participants, which included health care providers, academicians, health policy makers, Regional Cancer Center representatives and most importantly the aboriginal community leaders, were to address the burden of Cancer in the Aboriginal Populations of Canada.

The workshop considered several challenges in Cancer prevention and control that are specific to the Aboriginal population. Some of the issues that are unique to Aboriginal Populations are [6]:

1. A “highly complex, fragmented and less efficient” health care system that operates under provincial, federal and First Nation Jurisdictions;
2. Surveillance and Administrative databases cannot identify Aboriginal Population;
3. National health surveys exclusion of reserves and the territories;
4. Cancer is not clearly understood to common people as “culturally appropriate” information is not readily available;
5. Because majority of the Aboriginal population are young, the current incidence of cancer is low in comparison. This has resulted in a belief among the people and literature that cancer is rare in Aboriginals contributing to late diagnosis and misdiagnosis; and
6. Lack of research and cancer surveillance data that are specific to Aboriginal Population.

3.1 Data Collection Challenges

Some of the key issues that need to be tackled are political and ethical issues in reference to ownership, control, access and possession (OCAP) of the collected data and Privacy, Confidentiality and Security concerns. Positive partnership and trust among the various

stakeholders would also be a critical factor to consider. The main challenge in data collection would be to have complete co-operation of the people themselves. This is a challenge due to the perception among the Aboriginal people that data could be misinterpreted and misused by the media to misinform the rest of the Canadian population. Long term funding would also be an important enabler for continuity of the projects. Also, due to the distinct and diverse population of the aboriginal people data is simply not gathered separately for each group, therefore there is an absence of reliable data.

Though there are a number of “indirect” ways by which “Identification” data could be extracted from provincial databases such as linking of health card numbers to health insurance databases and using geographic indicators like postal codes to identify residency in a reserve. This data could be used to study system utilization by Aboriginals and for outcome analysis. However, there are privacy and ethical issues that need to be considered when it comes to data collection and management without “prior consent”.

Data Collection issues can also be addressed by ensuring better access to care to Aboriginal populations living in reserves and remotes areas of the nation and by building strong partnerships. [7]

In a health care setting the challenges in collection of ethnic data at the “point of care” are both System level and Encounter level. Some of the priorities to successful collection of ethnic health data in a hospital setting are:

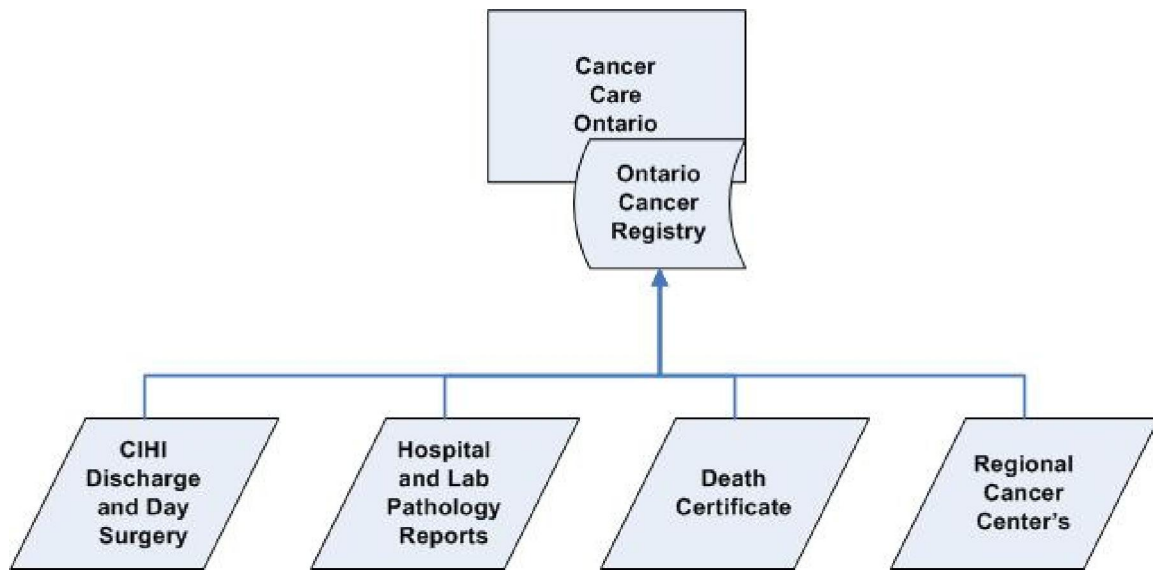
- Standardization of categories – Collecting standardized data across the entire system can help decision and policy making that could improve the quality of health care. Standardizing helps to collect consistent, reliable data that can be shared and comparable between regions. It can also make the data collection and data entry process coherent and simplified, minimizing chances of introducing errors.
- Clear understanding of the purpose of data collection – It is very essential to the success of the project that both the patient and the health care provider, primary

health nurse, clearly understands the goals of the project. As the issue of ethnicity is very sensitive, it is likely that there would be unwillingness on the part of the patient to answer the questions and a degree of discomfort on part of the nurse who is collecting.

- Providing response categories that are descriptive – The choices that are provided should be sufficiently descriptive. The system should be able to accept the response by having space for fields.
- Privacy, Confidentiality and Security of the health data that is collected, stored and disseminated.

4. Cancer Care Ontario's Aboriginal Cancer Unit

Canada is one of the very few nations in the world having a comprehensive national system of cancer registries. High quality data is collected by each province and territories which is combined to produce a Canadian Cancer Registry covering the entire country. Ontario has the largest indigenous population and also has a well established province wide integrated cancer control system by way of Cancer Care Ontario (CCO). CCO took the initiative and created the Aboriginal Cancer Care Unit which would work to improve cancer care for First Nations, Metis and Inuit people with a holistic approach and improve the access to cancer services, support, education and prevention. [8]



The Ontario Cancer Registry maintained by CCO stores cancer data from four sources: Canadian Institute for Health Information (CIHI)'s discharge and day surgery data, hospital and lab pathology reports, death certificates and data collected from the regional cancer centers. However, The Ontario Cancer Registry does not include any method to identify the Aboriginal population.

A "Needs assessment" of Ontario's aboriginal communities was conducted by CCO which identified specific cancer needs of the population thereby leading to the

formulation of the Aboriginal Cancer Strategy (ACS). The ACS identified priority areas that were to be addressed such as the need for culturally relevant prevention and educational programs and for more data about the burden of cancer in Ontario's Aboriginal Population.

Cancer Care Ontario in partnership with the Ontario Ministry of Health and Long-term Care (MOHLTC) and the Regional Cancer Programs took the initiative to design and run the 'Aboriginal Population data indicators pilot project'. This initiative was further developed with the Thunder Bay Hospital – Northwestern Regional Cancer Centre and the Juravinski Cancer Centre (JCC) at the Hamilton Health Sciences. These two Regional Cancer Center's were specifically chosen because of the large population of Aboriginal people in the respective local Health Integrated Networks (LHINs) service area.

5. Aboriginal Population Data Indicators Pilot Project

5.1 Objective

The Aboriginal Population Data Indicators Pilot Project would capture data on Aboriginal status (First Nation, Métis, Inuit) for all patients in the Ontario Cancer Registry.

The Aboriginal Population Data Indicators Pilot Project was rolled out to develop and evaluate a data collection tool to identify Aboriginal status of Cancer patients visiting the two regional cancer center's selected by Cancer Care Ontario (CCO). Hamilton and Thunder Bay areas were chosen because of the large Aboriginal populations in the respective LHIN's.

The objective of the project is to gather quality cancer specific data on Aboriginal people and to use the data to extract knowledge that would aid in decision making and policy planning which in turn would improve the health status of the Aboriginal community.

5.2 Significance of the Project

As noted by O'Neil and Blanchard (October 2001) in their paper prepared for the Assembly of First Nations Health Secretariat, "Considerations for the Development of Public Health Surveillance in First Nations Communities", it is recommended to run a pilot before country wide implementation of a surveillance project targeting the Aboriginal population that is unevenly widespread across the nation.

The potential benefits derived from the pilot project include:

- Demonstrate to Aboriginal providers, organizations, and communities the value of collecting and analyzing data on Aboriginal health:
 - This information can assist in improving the health status of Aboriginal people and the quality of care they receive in Ontario. Furthermore, it will help the cancer centre to gain a better understanding of the cancer care needs of the Aboriginal populations served in their areas.
 - This information can also be used to see which groups are being under-served, for example if their cancers are being caught at later stages. This will give us the kind of information as to which groups may need to be targeted for better services.
- The questions on Aboriginality may be applied to produce data about other health services at a later date;
- This project may also provide a template for developing other sources of data on Aboriginal health.

5.3 Project Description

This is a three month pilot project starting June 2009 and ending 30 September 2009. There are two pilot sites participating in this project, the North Western Regional Cancer Center in Thunder Bay and Juravinski Cancer Center (JCC) at Hamilton Health Sciences, Hamilton. Each has a relatively large Aboriginal population in their service area. The Northern RCC in Thunder Bay serves smaller or more rural/remote Aboriginal communities and JCC represents a southern RCC serving larger or more urban communities. The regional cancer centers were chosen because more than 60% of the cancer patients visit the center and there is direct patient contact by the data provider. Both NWRCC and JCC had previously shown engagement and support from Aboriginal communities in the region.

5.4 Project Activities

The Project team from CCO worked with the Sites team in sharing the project tasks and responsibilities. CCO was responsible aggregating the data and once the three data submission was complete, produce an evaluation report addressing the reliability and validity of the process. The activities of the project at Juravinski Cancer Center included developing the Data Indicators Tool, Training of the Data Entry personnel, Testing on the CPOE system, and Data Upload to CCO. Data would be collected for a period of three months, July to September 2009.

Several discussions were held between the CCO Project team and the RCC teams that included Managers from Nursing, Supportive Care, Cancer Informatics and also a Patient Navigator. Presentations were given to the nursing and other staff that would be directly involved in the project. The purpose of staff presentations was to explain the project so the staff could effectively answer any questions that the patients may have. The JCC Patient Navigator gave community presentations and also involved the Aboriginal Authorities.

It was decided that the tool would be color coded and would be sent out along with the patient package with instructions and information about the questions. The patients would complete and bring the sheet with rest of the patient forms at the time of their appointment.

5.5 Data Indicators Tool

The goal of the tool or Questionnaire was to obtain identification data from patients who visit the Cancer center for consultation or treatment. The tool had three questions targeting patients who identify themselves as Aboriginals. The Identification Questions were based on the recommendations from Statistics Canada's "Report on Regional Discussions on Aboriginal Identification Questions 2008". [9]

It was of concern that purpose of the questionnaire would be misunderstood by the target populations and they would choose not to answer the questions at all or answer incorrectly. Therefore, the question wordings and definitions were meticulously planned and designed so that it would not confuse or raise objections in the minds of the patients. Adequate explanations were given to the purpose of each of the three questions.

5. 5.1 Designing Data Collection Tool

Although health care facilities across Canada are swiftly moving towards a “paper-less” documentation system, most facilities still collect patient data on paper and then is entered manually on a Hospital Information System. Often data collection forms increase the chances of errors thereby reducing the efficiency of the data collection and entry process.

Some of the priorities in the pilot data collection tool design were:

- *Design of the Questions:* As the questions are of sensitive nature to the Aboriginal population, care was taken to frame the questions appropriately. To ask too many or too few questions can also make a tool ineffective and the process redundant;
- *Checking for Completeness of the forms:* To make sure that the forms that are returned by patients are checked for completeness at the point of care is an essential step in the data collection process. This would ensure reliability of the collected data;
- *Standardization:* Data collection process at the two pilot center’s should be standardized in order to make sure that data is comparable;
- *Errors in data entry:* Errors during manual entry of the data in to the system is a common issue that needs to be prevented. Sufficient training time has to be made available to the data entry personnel; and
- *Privacy, Confidentiality and Ethical issues:* The questionnaire has to be compliant with the privacy and confidentiality regulations because the tool deals with identity of the patients.

5.5.2 The Data Collection tool Questionnaire.

1. **Do you identify yourself as Aboriginal?** (*An Aboriginal person is a North American Indian, a member of a First Nation or who is Métis, or Inuit. North American Indians or members of a First Nation include status, treaty or registered Indians, as well as non-status and non-registered Indians.*)

Yes

No → go to END

Don't know

Prefer not to answer → go to END

2. **Do you consider yourself . . . ?**

First Nation → Status

Métis Non-Status

Inuk Other, please specify: _____

Other, please specify: _____

Prefer not to answer → go to END

3. **Is your permanent address on a First Nations territory or reserve?**

Nations territory or reserve?

Yes

No

Prefer not to answer



5.6 The Data Collection Process

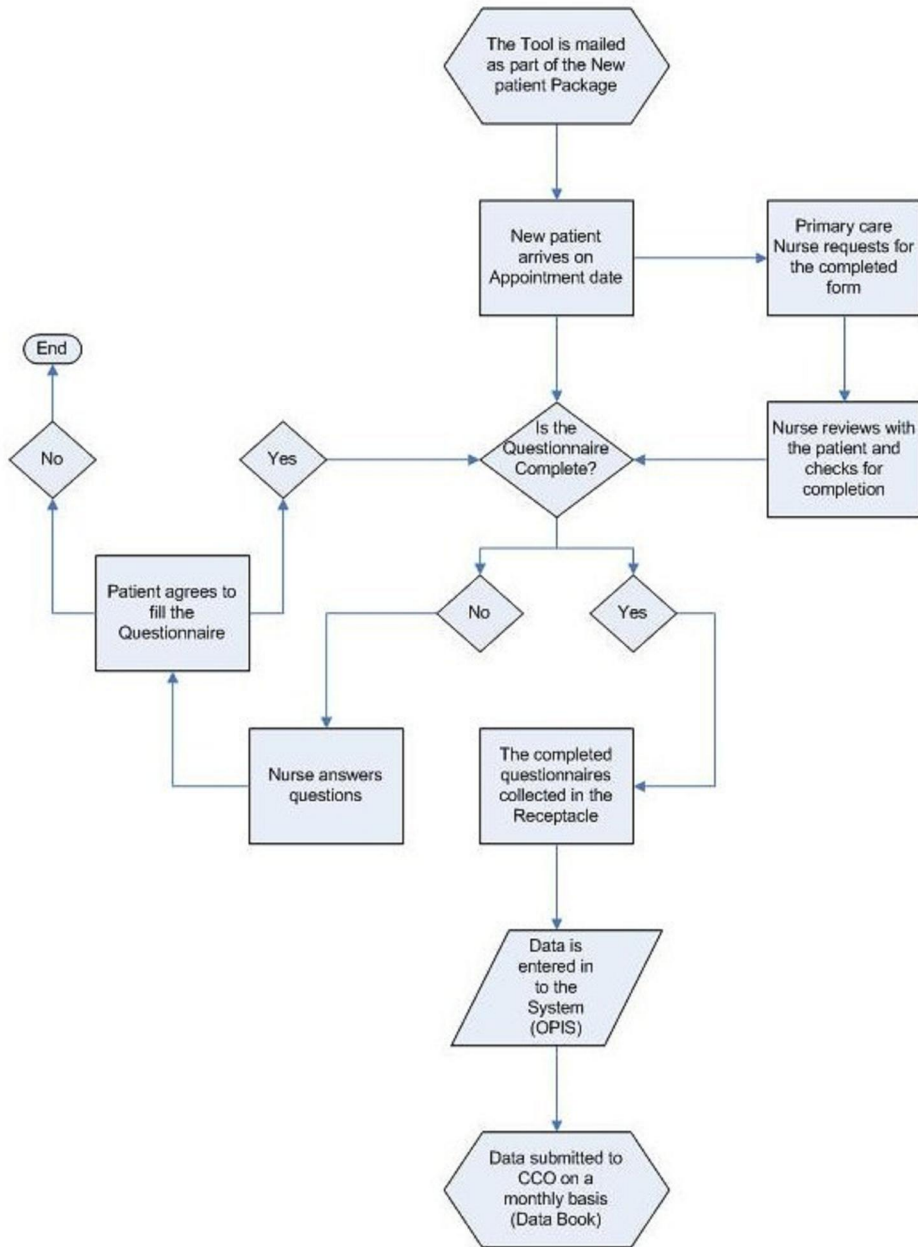
The questionnaire in color coded form is included in the new patient package that is sent out to all new patients to the center by new referral staff. Each questionnaire would be labeled with patients name and hospital chart number. On the day of the patient's appointment, during the initial assessment, the primary care nurse will request for the completed form. If the form is not completed or if the patient has any objections or questions, the nurse answers them in the best possible way following a guideline. Forms are collected daily and entered in to the Oncology Patient Information System (OPIS 2005). OPIS 2005 is Ontario's province-wide cancer specific Computerized Physician Order Entry (CPOE) system designed and implemented by CCO. It was designed for use by physicians, nurses and pharmacists to increase patient safety and offer clinical decision support.

5.7 Aboriginal Data Standardization

One of the main priorities that were set out by CCO to ensure data quality, was to collect standardized data from the two centers. It is also important that data is comparable and interoperable regardless of data being collected at different centers. Enabled by a standardized Oncology Patient Information System OPIS 2005 being used across the province, on which the data would be entered, it was possible to accomplish the task of building a standard dataset.

Aboriginal Data Indicators Pilot Project

Data Collection Process Flow



Aboriginal Data Standard Table

Data Element	Definition	Format	Valid Values	Purpose and Use
Submitting Hospital Number	MOHLTC facility number of the healthcare facility that is submitting the information.	CHAR 4 Numeric	Valid MOHLTC facility numbers only. Same 3-digit number that is used for MIS submissions. An additional leading zero is acceptable.	Uniquely identifies the hospital organization reporting this patient.
Visit Hospital Number	MOHLTC Master Number identifying the hospital site where this visit occurred.	CHAR 4 Numeric	Same as CIHI's Institution Number for NACRS or DAD submissions, but does not include CIHI's provincial identifier digit. For current valid MOHLTC master numbers, see Appendix A in Data Book .	Allows the hospital organization submitting the data to be distinguished from the hospital site where the service was delivered
Patient Chart Number	Patient identifier code that is unique within the healthcare facility.	CHAR 10	Consistent with CIHI NACRS and DAD definition and format.	Uniquely identifies a patient within an RCC. Necessary to determine a case. Foundational to most measures and indicators.
Health Card Number	Patient's most recent health insurance number assigned by their provincial government of residence.	CHAR 12 Alpha-numeric	The following Values are only to be used when unable to provide a Health Care Number. 0 = insured resident of reporting province, but HCN not available 1= not applicable, includes: Out of province resident with unavailable HCN, Out of Country, no health insurance coverage from province of residence	To identify OHIP vs. non-OHIP patients. Also used for registry linking.
Health Card Version	Version number of the patient's most recent provincial health card.	CHAR 2	As per MOHLTC OHIP rules.	Used for registry linking.
Patient Surname	Patient Surname	CHAR 50	Truncate if name longer than 50 characters	Required for the Ontario Cancer Registry to allow linking with other datasets (e.g. death registrations).
Patient First Name	Patient first given name	CHAR 40	Truncate if name longer than 40 characters.	Required for the Ontario Cancer Registry to allow linking with other datasets (e.g. death registrations).
Patient Birth Date	Patient birth date.	YYYYMMDD	Valid dates only.	For analyses involving patient age and registry linking.
S1	Do you identify yourself as Aboriginal?	CHAR 30	Yes No I don't Know Prefer not to answer	To define Aboriginal Population
S2_First_Nation_Status	Do you consider yourself?	CHAR 5	Yes No	To define Aboriginal Population
S2_First_Nation_Non_Status	Do you consider yourself?	CHAR 5	Yes No	To define Aboriginal Population
S2_First_Nation_Other	Do you consider yourself?	CHAR 30	NA	To define Aboriginal Population
S2_Metis	Do you consider yourself?	CHAR 5	Yes No	To define Aboriginal Population
S2_Inuk	Do you consider yourself?	CHAR 5	Yes No	To define Aboriginal Population
S2_Other	Do you consider yourself?	CHAR 30	NA	To define Aboriginal Population
S2_Prefer_Not_To_Answer	Do you consider yourself?	CHAR 5	Yes No	To define Aboriginal Population
S3	Is your permanent address on a First Nations territory or reserve	CHAR 30	Yes No Prefer not to answer	To define Aboriginal Population

5.8 Data Entry Testing and Training

Before entering on the system, it was important to do data entry in a test environment. The purpose was to make sure that the process was smooth and glitch free. At the JCC, it was decided not to enter data in to the system at the point of care. As this was a pilot and not a set process yet, to add this work to an already overworked primary nurse seemed futile at this point. Data entry staff was trained to make sure that errors are avoided or minimized.

The Data Entry steps:

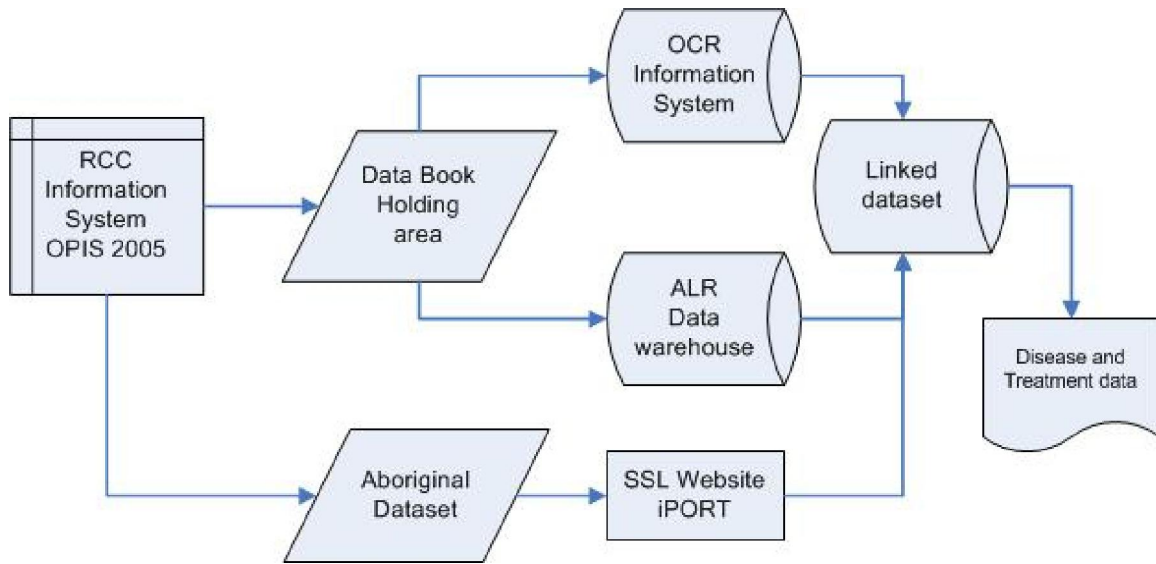
In OPIS:

- Ø go to the PABS screen
- Ø Enter the patient case number press F1 to Query
- Ø K4 to Add
- Ø Answer the questions below: and click return after entering the response
- Ø Question 1:
 - Y = Yes
 - N = No
 - U = Unknown
 - R = Refused
- Ø Question 2: and click return after entering the response
 - FNS = First Nation (Status)
 - FNNS = First Nation (Non-Status)
 - FNO = First Nation (Other)
 - MET = Metis
 - INUK = Inuk
 - OTH = Other
 - REF = Refused
- Ø Question 3: Click return after entering the response
 - Y = Yes
 - N = No
 - R = Refused

- Ø Comments can be added in free text up to 160 characters.
- Ø Click K4 to commit
- Ø Click K1 to enter the next patient.

```
OCDB.HRCC.HHSC.CA:TELNET - K-95
PABBS PATIENT ABORIGINAL STATUS 20-JUL-2009
CHART: 04-
Surname: First: DOB: Sex:
1) Has patient identified him/herself as aboriginal?
2) Aboriginal Group:
   If group is First Nations (Other), please specify:
   If group is Other, please specify:
3) Permanent address on reserve?
If patient refused to respond to some or all of the above questions relating
to aboriginal status, briefly state why:
K1Execute K2 K3 K4 K5 K6
Enter CHART number.
Count: *0 <Replace>
UT320 Help: Alt-H Prompt: Alt-X ocdb.hrcc.hhsc.ca:telnet TELNET
```

5.9 Data Submission Process



Once all the data has been entered in to the RCC Information System OPIS 2005, the data is uploaded to CCO's linked data warehouse. This is done along with the monthly Data Book upload by the RCC to CCO though the CCO's secured web portal (iPORT).

6. Next Steps

The Pilot has been planned for a period of three months and is due to end in September 2009. It has been decided that London RCC would continue collecting the data as the data collection process has seamlessly integrated in to the Hospital Information System's patient registration process. JCC would not be continuing with the data collection once the pilot period ends. This is because the region is in the middle of a system migration and adding a new process at this time would mean additional changes needed to the planned migration.

CCO would ensure that the data collected is relevant and valid and would engage in compilation, verification and reporting of the comparable data. A new initiative by the Ministry to evaluate the efficacy of the suggested outcome and methodology would be

undertaken. This would pave the way for a Pan-Canadian initiative that includes the entire country.

If the decision is to continue with the data collection, then the scope and usefulness of the data can be realized. As the volume of data collected increases, new knowledge can be generated, patterns can be studied and trend analysis could be conducted.

Potential areas for future development include expanded the data collection to other ethnic groups in the province or nationwide. Though there will be objections due to the race factor.

This vision can only be realized if we work together with the Aboriginal people as success depends on the collaboration and cooperation of governments, regional and local health organizations, key data custodians, and Canada's health research community.

Proposed Engagement of Aboriginal Communities includes:

- All Provincial Territorial Organizations (PTOs) will be kept apprised of developments through CCO's advisory committee the Joint Ontario Aboriginal Cancer Committee (JOACC) which is meeting in May of 2009.
- There are plans to inform representatives from Aboriginal groups: Métis Nation of Ontario, Aboriginal Health Access Centres (AHAC), Friendship Centres, and Chiefs of Ontario.

6. Projects Relationship to Health Informatics – A discussion

In a 1998 study by Anderson and Kirkham, “Constructing nation: the gendering and racializing of the Canadian healthcare system”, the authors analyzed the complexities of the Canadian health care system in relation to self-identification of ethnicity at the point of care. Though Canada is known in the world for its universal healthcare system having equal access to care and utilization of services for all of its residents, Anderson and Kirkham were able to show that significant inequality and widespread health disparity exists in ethnic Canadians. [10] Similarly, a report by the Institute of Medicine (2002) clearly identified the need for accurate data collection, reporting and continuous monitoring of patient care data in order to eradicate ethnic disparities in care. [11] With the rapidly increasing use of Health Information Technology and Tools, huge amounts of health data are collected from every point in the complex journey of a cancer patient in the health system. Standardization and Interoperability of the data is a priority so that the data is comparable for performance evaluation and decision making.

As the Canadian health care system does not collect ethnic data, researchers have to rely on census data for all calculations on Aboriginal population. [12] This could result in incomplete enumeration and underestimating of the total population of Aboriginal communities across the country. Therefore, to be able to collect high quality data is the key to prevent inequities in health care.

The objective of Aboriginal Data Indicators Pilot Project is to study the feasibility of obtaining “Identification data” from all new cancer patients arriving at the two sites, JCC and NWRCC. The raw data that is collected will be fed in to the hospital’s Oncology Patient Information System (OPIS 2005) which is then fed in to CCO’s comprehensive data marts. The Informatics team at CCO would then extract the data and use Business Intelligence tools to do analysis and present reports to stakeholders and decision makers. An over view of the data flow is as follows:

important step because the nurse can check for any incomplete forms or invalid answers and help control the possibility of creating errors.

- Developing the Data Indicators tool or Questionnaire
 - Considerable thought went in to the framing of the tool as the questions were sensitive. Resistance from the Aboriginal population in answering question related to ethnic background was expected. Therefore, it was decided to follow the Statistics Canada format
- Processes that would prevent errors to maintain Data Quality
 - To reduce errors and maintain data quality is a critical component. Other than the primary nurse checking for possible errors in completing the form, measures needed to be taken to prevent errors in data entry. The solution was to provide sufficient training to the personnel who were entrusted with the job of entering data in to the system.
- Data Submission format
 - Once the data is in the Cancer system, processes were to be set up that would enable seamless uploading of the data to CCO's data book so that integrity of the data is not lost.

I was able to experience first hand, the importance of introducing a new process in to the workflow of the hospital staff. As this project was only for a short period, it was decided not to assign the primary nurse to enter the data directly on to the system at the 'point of care'.

7. Recommendations

The goal of the Aboriginal Data Indicators Pilot Project is to gather high quality cancer specific data on the Aboriginal communities of the two Ontario LHIN areas in Thunder Bay and Hamilton thereby improving the health status of the Aboriginal population and their access to quality health care. Although factors like low response rate and incomplete responses may hinder the intended use of the data, the overall outlook is optimistic - a right step in the right direction.

A few of the recommendations that could be suggested are:

1. *Inclusion of other race, ethnic and language groups* – If the outcome of post-pilot evaluation is deemed a success and if majority of the objectives were met, then implementation should ideally look at including other ethnic groups. Ontario has the largest growing population of Immigrants and citizen from other cultures. The data collected from this multicultural population would be of immense value when it comes to healthcare planning and policy making. Data collected should include information on race, ethnicity and language. Ontario’s general population, like the rest of Canada, is aging and that requires planners to envision programs and care plans that targets groups from various cultures, race, ethnicity and languages. [13]
2. *Use of GIS Mapping and Decision tools* – “Location” is one of the data markers in the questionnaire and having this Geo-Spatial component in the database can greatly increase the scope of the project. The use of Geographic Information Systems (GIS) to develop new strategies to design intervention programs is very promising. The idea of being able to represent on a map, a section of the geography where communities are having a higher incidence of a specific cancer and then be able to compare with another location would have immense visual impact on policy and decision makers. [14] GIS tools can also be used by decision

makers to target resources to specific areas where intervention programs would be most effective [15]

3. *Location data can be used in Telemedicine* – As most of the Aboriginal population is dispersed with a large number in remote regions of the country. In urban areas, the community is scattered between those that live on the reserve and those groups who choose to live elsewhere. As “Access to Care” is one of the most crucial factors in improving the health status of Aboriginals, technologies like Telemedicine can be employed to connect a care provider or a navigator with a patient living in inaccessible areas.
4. *Better Communication with the Aboriginal People* – More involvement of the Aboriginal Community in project planning and process developing could be considered. This would have more acceptances from within the community and the importance of this data and the project in helping the community get better access to care and drastically improve the health status.
5. *Developing a Native Cancer Registry* – Valuable cancer data can be collected and stored in a cancer registry similar to the Ontario Cancer Registry (OCR). This database should be linked to other national and provincial registries. The advantage of having a separate registry as oppose to maintaining a single is that the Aboriginal population can have ownership of the data. This might improve the compliance among the Aboriginals. Also help in conducting community specific, disease specific research and studies that might improve the health status of the Aboriginals. [16]

8. Conclusion

There is a belief among Aboriginal communities that they will not be affected by cancer. The Incidence rates for all cancers combined were much lower in Aboriginal people compared with general population and they do not even have a name for cancer. [17]

This myth might be busted as the Aboriginal population ages. It is estimated that the incidence of cancer among Aboriginal populations would jump in the next decade. Surveillance data can help in the design and development of cancer control priorities and assist in formulation of prevention and intervention programs. It is expected that this pilot project would demonstrate the feasibility of providing cancer surveillance data for Aboriginal populations. However, because of the vast differences in various groups of Aboriginals across the country, it might be difficult to completely and accurately identify the various groups of Aboriginals across the health system. [18]

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