CANADIAN ASSOCIATION OF PROVINCIAL CANCER AGENCIES

Accessing and Linking Cancer-Relevant Administrative Data: Back to the Future

CAPCA

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EXECUTIVE SUMMARY

Access to a rich source of linked data advances cancer surveillance and secondary use of data for health research. However, numerous reports of slowed progress in the use of health services utilization data to inform Canada's cancer control system as a result of cumbersome access policies and poor linkage between datasets resulted in the Canadian Cancer Research Alliance (CCRA) asking for a current state analysis to inform a potential position statement.

This paper summarizes the process undertaken by the Canadian Association of Provincial Cancer Agencies to articulate access policies and linkage issues from a cancer agency perspective. Individual interviews with data stewards were conducted in some provinces. However, the sheer number of data stewards for the basket of cancer-relevant administrative datasets that were included in this analysis resulted in the decision to speak with the most senior cancer registry staff person based on the assumption that they would know the policies and access issues for all the datasets of interest, or would know who to speak with to gather the information.

Access policies, where they exist, vary by dataset and by province. There is little uniformity of approach, and a significant number of barriers that, if unaddressed, have the potential to significantly slow health services and policy research. While we were unable to clearly identify all of the access policies, a number of previous attempts to study the magnitude of the problem resulted in many of the same observations and recommendations, including:

1. The challenges that researchers face attempting to find information about cancer-relevant administrative datasets and the policies that govern access to them, and the meticulous data access and approval processes that reportedly take 1-3 years to complete;
2. Evidence of promising approaches to streamline access to data within provinces (e.g. CD-Link). Unfortunately, there was no evidence of any similar attempts, whether successful or not, to harmonize or improve access to cancer-relevant administrative datasets for research involving multiple jurisdictions;
3. Multiple previous attempts to evaluate the magnitude of the problem highlight not only how complex this work is, but how important it is to define a specific action plan to address what have become well known and are now long-standing challenges; and
4. Eight specific actions that build on previous work, adequately resource a plan for the future, and explore opportunities to make information regarding datasets and access to them more uniformly available.

Due to the significant nature of this work, and limited time available, a more deliberate focus on the documentation of access policies as well as researchers perspectives would be worthwhile. Additional energy designed to seek a greater degree of support from the full spectrum of individuals and organizations vested in this issue for the recommendations in this report would also be beneficial.

INTRODUCTION

The Canadian Cancer Research Alliance (CCRA) comprises the custodians of the majority of the money invested in cancer research both from investment of taxpayer dollars from government and voluntary donations by the public and charitable foundations in Canada. Motivated by the conviction that collaboration between the funding agencies will maximize the collective effort and accelerate both scientific discovery and, importantly, the application of research findings to improve cancer outcomes, CCRA led the development of the *Pan-Canadian Cancer Research Strategy*.

Twenty-four key action items, grouped across eight thematic areas, highlight activities that would benefit from collective action and shared resources. As part of an overall contribution to the enhancing the efficiency and effectiveness of the cancer research community, the research strategy identified the need to improve access to cancer-relevant administrative datasets.

CCRA's Pan-Canadian Cancer Research Strategy, like many other reports, highlights Canada's rich repository of data. Based upon anecdotal information from the research community, it also highlights less than adequate "access and poor data linkage within and across provinces as significant barriers to conducting health services and prevention research where outcome data are key" (1).

Accessing cancer data is fundamental to much cancer research, and linked datasets provides a much richer source of information than single datasets typically allow. Therefore, CCRA identified Action Item #18, to "improve access to cancer-relevant administrative datasets, as a priority for action in year one of the strategy".

The Canadian Association of Provincial Cancer Agencies (CAPCA) was identified as the lead agency for this work. The Alberta Cancer Foundation (ACF), Cancer Care Ontario (CCO), Canadian Partnership Against Cancer (CPAC), Ontario Institute for Cancer Research (OICR), Direction de la lutte contre le cancer of the Québec Health Ministry, Cancer Care Nova Scotia (CCNS), Canadian Cancer Society (CCS), and Canadian Cancer Action Network (CCAN) were identified as partner agencies. The Canadian Cancer Society and Canadian Cancer Action Network both agreed to review the recommendations emanating from this work and to consider participating in their implementation as appropriate. Representatives from the remaining organizations comprised the Cancer Relevant Administrative Dataset Access Working Group (See Appendix 1).

Purpose of this Report

This report highlights a current state analysis report to CCRA regarding access to and linkage between cancer-related administrative datasets. Based upon the findings of this report, CCRA members will consider whether further action may be warranted.

Background

Disease surveillance, which dates back centuries, plays a vital role in the organization and evaluation of public health and disease prevention and control initiatives worldwide, and to effectively plan for service delivery. The ongoing collection, analysis and interpretation of data about cancer in Canada dates back to the 1940's when the first provincial cancer registry was established. Cancer agencies and registries play a vital role not only in the collection of information about people who have been diagnosed with cancer in each province and territory, but in analyzing the data, maintaining data security, and considering requests for access to information by various third party data users which includes researchers. Provincial cancer registry data is used to inform provincial cancer control efforts. Data from each provincial cancer agency is also reported into the Canadian Cancer Registry (CCR) to inform national cancer surveillance, multi-jurisdictional and pan-Canadian cancer control efforts, evaluation of population-based interventions, and to enable cancer control research.

Single datasets, like the Cancer Registry, contribute to cancer control in meaningful ways and linking datasets enables a greater degree of analysis than would otherwise be possible. For example, combining cancer registry data with information about:

- the timing of key events in the cancer journey (e.g. data of surgical procedure, or commencement of chemotherapy) enables closer scrutiny of wait times and better allocation of resources to reduce unnecessary delays across the cancer control spectrum, from access to diagnostic services through to palliation;

- screening, investigation, diagnostic, and therapeutic interventions enables evaluation of the adherence to clinical practice guidelines and standards of care, which may highlight the need for greater clinical education and awareness or alignment of incentives;

- pain and symptom management at the time of death facilitates evaluation of the effectiveness of palliative care interventions;

- HPV immunization rates will contribute to a greater understanding of the long-term effectiveness of vaccination programs on stage at diagnosis, as well as assessment of the impact of immunization on age-standardized cervical cancer incidence and mortality rates.

Cancer surveillance and cancer-related administrative data are utilized by a large and diverse number of groups, including provincial/territorial/federal governments; health care professionals; journalists and the media, educators, health care providers, and researchers. Typically, researchers use these datasets to provide evidence in a number of areas which include clinical and etiological epidemiology, pharmacology, health services research, and health economics.

These users consistently report the need for timely access to reasonably priced data in a way that preserves individual privacy.

Challenges in Health Services Research in an Information Rich Communication Poor Environment

Increasing concerns around for example, inequity in health and the growing knowledge of the multidimensionality of factors which affect disease risk, access to health care and health outcome, demand increasingly sophisticated approaches to the assembly, analysis and interpretation of data. For instance, answering an apparently simple question might require access to multiple datasets across two or three jurisdictions or even within a single jurisdiction. For example;

- It is known that the risk of second cancers, especially breast cancer in women is greatly increased following radiation treatment for Non Hodgkin Lymphoma. Understanding the extent of that risk, whether there is room to reduce that risk by moderating radiation exposure and to what extent women are receiving appropriate follow-up care would entail scrutiny of cancer registration, radiotherapy, breast screening and possibly physician billing databases.

- Comparison of use of breast-conserving surgery by age, stage and age-specific cohorts will become possible through the accessing of data that is becoming more widely available through cancer registry as disease staging and treatment information becomes more generally captured. However, additional data that is not already available via medial records or within the health care system (for example, the characteristics of care providers and their availability, personal risk factors, co-morbidities or baseline performance status) would need to be accessed and linked.

- Evaluation of impact of adolescent and young adult cancer treatment some 10 years post diagnosis requires information not only from cancer registries (age, stage of cancer at diagnosis, histology, initial surgery and radiation) but information about chemotherapy, management of co-morbid conditions, and healthcare utilization which requires access to multiple data sources.

Not the first to arrive: treading where others have been

Several attempts have been made to articulate the many and frequently complicated issues surrounding access to and linkage between administrative datasets for health surveillance and/or research purposes.

Auditor General of Canada

In 1999, the Auditor General's Report (2) emphasized the importance of health surveillance in enabling the planning, conduct and evaluation of health programs dealing with causes and treatments of disease. Many of the observations of this report remain unaddressed. For example, the report noted that each province and territory has its own public health and privacy legislation covering the responsibilities of disease surveillance and disease control which adds to the complexity of enabling effective surveillance at a national level.

Canadian Coalition for Cancer Surveillance - 2000

Between 1999 and 2000, research conducted for the Canadian Coalition on Cancer Surveillance by researchers at the Health Law Institute, University of Alberta, and the Centre de recherche en droit public at the Université de Montréal (3) summarized the legal context for cancer surveillance in Canada. As such, while the recommendations focus on legislative change, the authors suggest that the following observations and recommendations are worthy of attention. Only those relevant to access to or linkage between cancer related administrative data for research purposes are listed.

- the need for established criteria and process for, among a long list of issues, the rules regarding access to data for research purposes;
- The interdependence of changes in legislation and to health utilization databases on the ability of cancer registries to manage expanding roles, including analysis of data to monitor outcomes; and
- The variation in legislation regarding cancer surveillance, and the impact that this variation has on our ability to exchange and share data, echoing the Auditor General's previous report.

Canadian Institutes of Health Research (CIHR) - 2005

Funded by CIHR through a competitive RFP process, the Canadian Policy Research Network in partnership with the Centre for Health Services and Policy Research at the University of British Columbia completed an analysis of current or emerging issues with respect to collection, use, privacy, and access to population-based health and health services data, including administrative databases and registries (4).

The research team:

- reviewed current and emerging privacy and access issues
- conducted 43 interviews with 25 data collectors and custodians, as well as 18 users of population-based health and health services data. The interviews served to identify the range of issues faced by population-based health and health services research data collectors and custodians in developing and maintaining databases and in granting data access to researchers.
- reviewed conceptual frameworks for the development of electronic inventories of population-based databases;
- created a prototype data collection tool and online database; and
- released 10 recommendations to improve access to and use of data in the areas of population health and health services, including the need to:
  - coordinate activities to address privacy issues;
  - convene a coordinating body that will focus on improving access to population health and health services research data and be charged with carrying the recommendations forward. The fact that such a

group was not established may reflect the apparent lack of progress in some areas;
  - review organizational mandates with a view to clarifying and increasing commitment to provide data and other supports for population and health services research;
  - establish clear processes and equitable costing mechanisms to make data available for research purposes;
  - supporting the costs of conducting data-based research;
  - maximize efforts to improve access to research data;
  - develop, in collaboration with other partners, a web-based "population and public health and health services research" portal to host an electronic inventory and tools;
  - review commitments to building, populating, and maintaining an electronic inventory
  - develop a business plan for a portal and an electronic inventory, assuming continued support for these efforts is sustained.

Canadian Partnership Against Cancer Surveillance Advisory Group – 2008

Designed to build upon and review the analysis of the 2000 report commissioned for the Canadian Coalition on Cancer Surveillance, on behalf of the Partnership's Surveillance Advisory Group funded an analysis of legal and policy frameworks and options for enhancing surveillance (5). Like the 2000 report, model legislation, template policies and agreements, standards and guidelines, best practice statements, and consensus statements are identified, some of which deal specifically with access to data.

Canadian Longitudinal Study on Aging - 2009

Raina et al. conducted a research study to examine the "practical, methodological, and ethical aspects of accessing" healthcare utilization (HCU) databases across all Canadian jurisdictions to create a nationally integrated linked dataset. Fifty-three data stewards and privacy commissioners from federal, provincial and territorial jurisdictions were interviewed to gather qualitative information about the time, policies, and costs associated with HCU data access. Issus related to privacy and confidentiality of data, ownership, transparency and accountability were also explored. The researchers conclude by highlighting a number of challenges (i.e. variability in access processes) and suggestions (i.e. researchers should develop a close working relationship with data custodians).

Public Population Project in Genomics (P^3G) + Canadian Longitudinal Study on Aging (CLSA)

P3G is a not-for-profit consortium dedicated to fostering optimal use of research infrastructures and promoting collaboration between researchers in the field of population health. It has developed tools to compare and merge data from population-based studies internationally. It is also cataloguing studies biobanks and other data repositories as well as data collection tools and intends to make this information available on their publicly accessible website (www.p3gobservatory.org). As part of this work, , P^{3}G and the Canadian Longitudinal Study on Aging (CLSA) are documenting processes, design and type of governmental administrative information being collected by Canadian provinces that could be used for longitudinal health research projects in the context of CLSA and the Canadian Partnership for Tomorrow (CPT) project.

Building on previous work done by the CLSA (6), P^{3}G and CLSA staff is cataloguing information about 5 health care utilization datasets that could facilitate participant sampling and longitudinal data linkage for the CLSA and CPT project. Information about each of the following five datasets, generated through semi-structured interviews with data stewards in each province, were transcribed onto a Database Description Form (see Appendix 2):

- *Registered persons database*
- *Provincial physician billing database*
- *Physician registry*
- *Drug utilization (e.g. pharmacare)*
- *Hospitalization database*

Collectively, the observations and recommendations from a multiplicity of government, academic and policy groups over more than one decade illustrates not only how challenging it is to understand and then document access and linkage policies and approaches, but how much more challenging it may be to implement meaningful change. It also serves as a reminder that there are multiple potential partners who have wisdom and organizational knowledge to bring to bear.

THIS REPORT

Methodology

Soon after the approval of the Cancer Research Strategy in February 2009, a working group was formed with representatives of organizations who had expressed an interest in participating in the completion of this report. The Working Group defined the datasets that would be included in the basket of cancer-related administrative datasets, and met regularly at the beginning of the project to establish timelines, identify key informants, and to review the survey.

Design

A series of one-on-one qualitative interviews were held with individuals from provincial cancer agencies that were most likely to be knowledgeable about access to and linkage between the basket of cancer-related administrative datasets identified for the purposes of this analysis. Interviewees were sent a copy of a questionnaire in advance and given the option of completing it on their own, or completing it during a semi-structured telephone interview.

Interviews

Interviews with each of the key informants was designed to last between 45 and 60 minutes. However, after two interviews, it became evident that collecting information about the basket of datasets identified for this project from a single data custodian was not only impractical, but impossible. There are many custodians of data at the provincial and national level, including multiple departments within provincial governments and ministries. As a result of the breadth of this work, the Working Group elected to focus on access to and linkage between datasets from a cancer registry perspective. In hindsight, focusing on access and linkage from a health researcher's perspective may have been more instructive.

Additional Information

In some instances, additional information beyond that provided in the completed questionnaire or during the telephone interview was obtained in written form from key informants or from other sources. This additional information (e.g. data access processes) was more readily obtained from some provinces than others.

Information from the questionnaires and the interviews were collated and summarized by two Cancer Care Nova Scotia staff for the purpose of presentation. The results were compared against information available on provincial government websites, where available.

Cancer Registry Function and Location

Provincial cancer agencies and programs play a critical, though varied, role in cancer control in Canada. In addition to the responsibility for either providing cancer care and treatment, or establishing the standard for cancer care across a province, cancer agencies are also responsible for collecting, analyzing, reporting on, and providing access to cancer surveillance data through provincial cancer registries.

Canadian Provincial Cancer Agencies and Provincial Cancer Programs housing Provincial Cancer Registries and cancer surveillance programs:

British Columbia:	www.bccancer.bc.ca
Alberta:	www.albertahealthservices.ca
Saskatchewan:	www.saskcancer.ca
Manitoba:	www.cancercare.mb.ca
Ontario:	www.cancercare.on.ca
Quebec:	www.msss.gouv.qc.ca/sujects/prob_sante/cancer
New Brunswick:	www.gnb.ca/0051/cancer
Nova Scotia:	www.cancercare.ns.ca
Prince Edward Island:	cancercentre.pe.ca
Newfoundland and Labrador:	www.easternhealth.ca

The role and scope of activity of provincial cancer registries varies considerably, reflecting the availability of resources, number of tumours diagnosed (which is reflective of population size and cancer risk, among other factors), and extent and nature of follow-up information captured within the cancer registry.
Provincial cancer registries submit provincial data to the Canadian Cancer Registry (CCR) in accordance with NAACCR data standards. According to Statistics Canada's description, the CCR is:

> "…an administrative survey that collects information on cancer incidence in Canada. The CCR is a collaborative effort between the thirteen Canadian provincial and territorial cancer registries and the Health Statistics Division of Statistics Canada, where the data are housed. Ultimate authority and responsibility for the degree of coverage and the quality of the data reside with the provinces and territories. Beginning with reference year 1992, information collected by the provincial and territorial cancer registries has been reported to the CCR. The data that comes into the CCR describes both, the individual with the cancer, and the characteristics of the cancer.
>
> The primary objective of the CCR is to provide a large database to study cancer patterns and trends and to monitor differences in cancer risks among different populations. Information about cancer incidence and survival in Canada is generated by the CCR. The information is used for descriptive and analytic epidemiological studies to: identify risk factors for the cancer; plan, monitor and evaluate a broad range of cancer control programs (e.g., screening); and, conduct research in health services and economics.
>
> The CCR is a dynamic database, maintained at Statistics Canada, of all Canadian residents alive or dead who have been diagnosed with cancer. The function of the Canadian Cancer Registry is to produce standardized and comparable cancer incidence and survival data for each primary site of cancer. The CCR is a patient-based system, in which are recorded the kind and number (incidence) of primary cancers diagnosed for each person over a number of years until death. The advantage of this system is that longitudinal data is available for each cancer patient. New primary cancers occurring for previous cancer patients are identified. The patient data is regularly linked to mortality data so that the date and cause of death of every cancer patient is eventually known."

Given the central relevance of cancer registry data to health services research and assumed familiarity with access and linkage policies to cancer-relevant administrative datasets one person from each cancer registry was identified as the central contact for collection of information. In many cases, the central registry contact attempted to gather information from other data custodians with varying degrees of success.

The "basket" of cancer-related administrative databases

Provincial cancer agencies and programs were asked to provide information on the availability of cancer relevant datasets (listed below), additional to the core cancer registration data, and about issues around access and linkage to that dataset.

The datasets fell into 3 main categories:

Databases specifically detailing individual patient care

- CANCER CARE DATABASE
- SURGICAL ONCOLOGY DATABASE

- DRUG RELATED/PHARMACY DATABASE
- PHYSICIAN BILLING DATABASE
- HOME CARE DATABASE
- AMBULATORY CARE DATABASE
- DISCHARGE ABSTRACT DATABASE
- WAIT TIMES DATABASE
- OTHER RELEVANT PATIENT LEVEL DATABASES

Screening and Vaccination Databases

- BREAST CANCER SCREENING
- CERVICAL CANCER SCREENING
- COLORECTAL CANCER SCREENING
- HPV IMMUNIZATION DATABASE

Other Population Databases

- DEMOGRAPHICS AND POPULATION DATABASE
- VITAL STATISTICS

Other Databases

- TUMOUR BANK DATABASE

Exclusions

A comprehensive evaluation of access to and linkage between administrative datasets, including those that focus exclusively on cancer, would typically include an analysis of privacy and legislative issues; affordability of data access; the adequacy of resources required for ongoing database management; as well as perspectives from both data custodians and data users that highlight, among other issues, the timeliness of access. Resources were insufficient for this level of analysis. Well documented, thorough analyses of privacy and access issues are available and should be carefully reviewed as part of an overall approach to evaluating options to improve access and linkage between existing databases.

In addition, the original scope of this work included the capture of information on availability and accessibility environmental and occupational data sets. However accessing information about these datasets was extremely challenging, so have not been included in this report. The Canadian Partnership Against Cancer funded initiative, CAREX, has greatly advanced knowledge in this area. Additional information about CAREX is available at: http://www.carexcanada.ca/en/

Finally, the role of Research Data Centres has not been explored in this paper. Research Data Centres are part of an initiative involving Statistics Canada, the Social Sciences and Humanities Research Council (SSHRC), and university consortia. By providing access to microdata from population and household surveys, Research

Data Centres are designed to "help strengthen Canada's social research capacity and to support the policy research community".

Access Policies

Provinces are at different stages in their evolution; some policies exist and there is variation between them, while others do not have written policies. Whether the absence of a policy facilitates or hinders access is unknown. Those that do have policies have approached access differently, often reflecting variation in the interpretation of legislation.

Major Initiatives in Data Access and Linkage

CD-Link

A joint initiative between Cancer Care Ontario's Health Services Research Program and the Ontario Institute of Clinical Evaluative Sciences, CD-Link is modeled after the U.S. SEER-Medicare program whereby individual level patient data housed by cancer registries are linked to a variety of administrative datasets.

CD-Link is designed to make standing linkages of existing data sources available as an infrastructure resource for cancer health service researchers, and to put de-identified, linked data directly into the hands of researchers. Access to CD-Link is currently only available to researchers at Ontario academic institutions but expansion is anticipated. Linked data from the following datasets is currently available:

- CIHI – Discharge abstract database (DAD)
- CIHI – National Ambulatory Care Reporting System (NACRS)
- Home Care Database
- Ontario Drug Benefit Claims (ODB)
- Ontario Health Insurance Plan Claims Database (OHIP)
- CytoBase (Cervical Screening)
- Ontario Breast Screening Program (OBSP)
- Ontario Cancer Registry Information System (OCRIS)
- Registered Persons Data Base (RPDB)

A summary of the application, review, agreement, data transmission and end of analysis process is available as Appendix 3. Other models of single point of access exist, but to the best of our knowledge do not include access to cancer registry data in the way that CD-Link does.

Manitoba Centre for Health Policy (MCHP)

The Manitoba Centre for Health Policy is a research unit in the University of Manitoba's Faculty of Medicine. Approximately half of its funding comes from five-year contracts with the Provincial Government for specific research projects.

To facilitate access to administrative, registry, survey and other databases, MCHP houses and maintains the Population Health Research Data Repository which houses a collection of healthcare, social, education, some registry[1], and justice (incident reporting system)databases (Appendix 4). Manitoba Health is the primary health data provider for the administrative, survey and clinical databases that fall into the "healthcare" collection. The repository provides a description of each database using a standardized template, including data provider/ agency, purpose and method of data collection, database size, calendar years for which data are available, scope of the database, access requirements, and database highlights (see example at Appendix 5).

MCHP acts as a single coordinating body for those wishing access to databases housed within the Repository. According to information provided by MCHP, the 4 step application process takes a "minimum of 4 months from initial submission of proposal to receipt of all necessary approvals to access the data" but that the time required will depend upon availability of the approval committee, completeness of the application, as well as other factors. MCHP does not facilitate access to similar databases from other provinces, so researchers conducting research across multiple jurisdictions must follow access and linkage policies and processes for each additional database they require access to, as well as any additional research ethics and privacy review processes within their institution, at the provincial level (e.g. Health Information Privacy Committee in Manitoba), and in other provinces.

Population Data BC

Population Data BC is BC's first pan-Provincial population health data service that provides data linkage and access. Internal data holdings include population and demographic data, occupational data, early childhood data, and health and health care services[2] data. The initiative is funded by the Canadian Foundation for Innovation, the Michael Smith Foundation for Health Research, and the Ministry of Small Business, Technology and Economic Development Fund, and includes five data partners (among them, the BC Cancer Agency) and six partners.

The health care and health services data holdings include:

- Medical Services Plan Payment Information (MSP)
- Pharmacare
- Discharge Abstract Database (Hospital Separations)
- Home and Community Care (Continuing Care)
- Mental Health
- BC Cancer Agency, including the BC Cancer Registry

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[1] MHCP does not house Manitoba Cancer Registry data. Access to the cancer registry dataset is managed by CancerCare Manitoba registry and epidemiology staff.

[2] Health services data previously held by BC Linked Health Database is now available through Population Data BC.

Vital statistics data (birth, marriage, death, and stillbirths), occupational-related injury data, and early childhood data are also included.

Population Data BC provides a single point of access to its internal data holdings, but it does note that even a meticulously completed data access request the time between submission and data delivery “may take over a year”.

An internal Education and Training Unit provides free online workshops (e.g. Admin Data 101, Space-Time Disease Surveillance), best practices tools and other resources for data users, and professional specialization certificate in health data analysis.

Main Findings

There is a great deal of data collection occurring and several very promising approaches in BC, Manitoba and Ontario to provider easier access to, among other areas, health utilization data. However, what is far less clear is whether there have been any attempts to better coordinate access to data across jurisdictions or whether data stewards from provinces where access to each database is separate, rather than through a single point of access, have had the opportunity to learn about initiatives in other parts of Canada.

Furthermore, there appears to have been a series of starts and stops; various groups have recognized that access to and linkage between health care utilization data for research purposes is not optimum. Several groups have attempted to articulate part or all of the problem and have offered carefully considered advice. The path from each of these initiatives, however, has quickly become buried. As a result, as was the case with this attempt to describe access and linkage to a defined set of databases, initiatives appear to start without much of the benefit of past experience.

As a result of these observations, and due to the fact that even for this initiative we became aware of information about previous attempts to articulate both the problem and potential solutions late in the process, there is some degree of overlap. Rather than focus on implementation of solutions that remain promising but untested, there is more work to do to understand where others have been and wish to go.

Our major observations are:

- All Provinces invest substantial resources in the creation and management of a number of databases across a number of agencies. The extent to which these data can be brought together to provide policy and practice relevant information is constrained by technical, administrative and bureaucratic procedures and a limitation of resources. The capture of important and highly relevant information will no doubt increase in the future but with the current structures and processes there is no guarantee that this will be translated into useable information.

- There is substantial variation between provinces both in the extent of data captured by the provincial cancer registries and in the range of data sets available to them.

- There is substantial variation in the accessibility of data both within and outside the cancer agencies. This appears to have more to do with the regional culture of data sharing and whether the data user is considered "internal" or "external" to the organization housing the database, than whether there is a written policy regarding access. This echoes an observation of the CIHR report, "Data, Data, Everywhere…." Improving access to population health and health services research data in Canada".

- The length of time between a users request for data and transfer of the data for research purposes can be long. Even when data access requests are meticulously completed and submitted through a single access point, such as Population Data BC, approval and data transfer can take more than one year. In fact, users report that a "wait of one to three years for access approval was not uncommon. A number of researchers complained that by the time their request was approved and they received the data, the period of their grant funding had expired. One participant spoke of "ministries starving you to death waiting for permission". *Data Data Everywhere*.

Summary of Challenges

This apparently straightforward task proved in fact to be enormously challenging. Our experience collecting information about these datasets and describing the access and linkage processes are similar to many others:

- For this report, not being able to readily identify the appropriate key informants. As a consequence, even though we were guided by the advice of knowledgeable provincial experts, considerable time was spent just trying to identify and then connect with the right people. Independent researchers, particularly more junior investigators, would not necessarily have the knowledge or the access that we had which may further complicate and lengthen the process of searching for relevant datasets.

- Due to the complexity of health care utilization data collection, organization, and storage across Canada, interviews with multiple provincial data custodians were frequently required.

- Significant diversity in the way data is captured, collected, stored, and maintained and the policies that govern access and processes required to link datasets. For this report, this presents a significant challenge trying to document the information structures of different provinces within a common framework. For individual researchers contemplating multi-jurisdictional research involving multiple databases, it presents a potential imbalance between the time required to gather access to data and the time available for research and analysis.

- The length of time between completing this preparatory work and receipt of data has been estimated to be between "several weeks to 12 months". In fact, anecdotal information suggests that access can take as long as two years. It would seem entirely possible that the lengthy time required to access data limits researchers ability to do what they do best: research. Instead, they spend time navigating a complex web of processes and policies, and then they spend considerable time waiting. Any increase in demand for data without a corresponding increase in the availability of data stewards may lengthen the waiting process. Together, these challenges may even potentially render some studies unachievable.

- The move towards synoptic reporting and electronic health datasets will greatly increase the potential for relevant data capture and linkage but may present enormous challenges in processes for data access and specialist capacity to deal with these data meaningfully.

- For researchers, the costs associated with accessing multiple datasets, whether within a single jurisdictions and across multiple jurisdictions, can be prohibitive.

- The extent to which important information relevant to the organization of the delivery of cancer care, the monitoring of quality of care and the support of advancement of knowledge in clinical, health services and population research is not uniform across Canada. This greatly burdens the development of evidence based policy in all aspects of cancer control both at the Provincial and Canadian level.

- There are substantial differences in policies around data access both for the cancer registries and for other parties. While it is important to safeguard privacy and support data privacy and protection legislation it is also important that cancer registry and other cancer relevant datasets are able to be used in a timely way to support cancer control and evidence based decision making.

Considerations

Any recommendation designed to improve access and linkage may have an impact on the use of data and therefore on custodians of that data. The impacts of greater use need to be carefully considered as part of an overarching vision so as not to create bottlenecks in the system. Several initiatives implemented by Statistics Canada (Data Liberation Agreement, Research Data Centres, Remote Data Access

Program) have reportedly led to a “sharp increase in the use of Statistics Canada archive of health-related data resources.

Cautionary Notes

While this paper was reviewed by each of the individuals who contributed to its creation, there was insufficient time to ensure uniform support for each of the following recommendations across each of the provincial cancer agencies or by all the data stewards who would be involved in the basket of datasets included in this report. It was not clear that the magnitude of the problem regarding access and linkage is uniformly felt by researchers or data stewards across the country. As a result, further discussion was encouraged before jumping straight to the identification of solutions. More specifically, since more than one individual felt that the recommendations were beyond the scope of the mandate given to CAPCA by CCRA it is important to note that it may still be worthwhile to document access policies and linkage between a (smaller) defined group of datasets.

RECOMMENDATIONS

Recommendation 1 Sharing Current Knowledge

CCRA or some other pan-Canadian organization representing the advancement of cancer research in Canada should take a lead in coordinating a series of activities to ensure that attempts to improve access and linkage between healthcare utilization datasets are analyzed and well understood. This would include:

- Literature review to identify additional attempts in other areas of health care, or within the area of cancer research, to evaluate options to improve access or linkage, or to implement change.
- An assessment of the impact of data access and linkage efforts on data custodian workload and ability to provide access to data in a timely manner
- A meeting of the authors of the CIHR 2005 report, P^{3}G and CLSA teams whose work is described in this paper; and interested CCRA members at a minimum to learn more about previous work.

Recommendation 2 Establish Ownership and Governance and Allocate Funding

CCRA or some other pan-Canadian organization should convene an adequately resourced Task Force/group that would be accountable for defining and delivering on a specific course of action to move this agenda forward. A thorough review of previous and current attempts to improve access and linkage across the health sector (e.g. beyond cancer) and across jurisdictions should be provided to ground this group’s work. In addition to the initiatives listed, information about the Manitoba Centre for Health Policy’s Knowledge Data Sharing Working Group may be instructive and should be explored.

Recommendation 3 Build a pan-Canadian network of data stewards either specific to a particular type of dataset (pharmacare or home care) or generic to health datasets.

CCRA or some other pan-Canadian organization should create a mechanism for data stewards with responsibilities for similar databases should be connected in a meaningful way so they can share progress, policies, and procedures, and so there is a natural environment to begin to address access and linkage in partnership with the custodians of data. An initial meeting of data custodians at the provincial and national level could be convened to begin the process of simplifying access to cancer-relevant administrative data for trusted parties, including cancer agencies, from which a network of data custodians could be established. Given that not all networks prove to be of value, the network should be evaluated after an appropriate period of time.

Recommendation 4 Agreement to focus on increasing access to health datasets within and across provinces.

CCRA or some other pan-Canadian organization should convene a workshop designed to: 1) discuss the feasibility of harmonizing access policies; and 2) establish a policy on privacy and data access, including a more consistent interpretation of privacy legislation as it relates to cancer-relevant and health care utilization administrative health data. Data custodians, health services researchers, privacy officers, and funding agencies that support health services research should be among those considered critical to the success of this meeting. Beginning with a specific type of database (e.g. pharmacare or home care) would enable approaches to be tested and refined, before being applied or evaluated for broader use.

Recommendation 5 Seek support for single point of access to centralize information about basket of datasets (access to data versus access to information about data)

CCRA should work with its partners to evaluate support for a web-based health care utilization and public health related administrative datasets portal to house an electronic inventory as well as related tools to support the research community to use existing data resources efficiently and in a privacy-sensitive manner. Increasing access to information about data appears to be an important issue to address, but additional steps are required to improve access and linkage. Information alone will be insufficient for these broader objectives. If data stewards agree to the principle of online provision of information about their dataset, as they appear to have done in BC and Manitoba, a business case with objectives, options and a preferred model, host agency, ongoing funding, and evaluation need to be articulated.

Recommendation 6 Assuming there is support for a repository, develop a business case

Options for a pan-Canadian repository should be carefully explored with CIHR, PHAC, the Canadian Cancer Society Research Institute, and Health Canada as major stakeholders. Developing capacity (data quantity and quality, intraprovincial linkages) and ensuring the availability of appropriate resourcing seems to be a priority at this stage.

Recommendation 7 Engage with patient advocacy organizations about the important of cancer research - change culture

Research and evaluation play essential roles in the understanding of health and the delivery of health care. The public and patients need to be better informed of the nature of data-based research and evaluation so that it is better supported and valued. Organizations like the Canadian Cancer Society and Canadian Cancer Action Network can play a critical role in facilitating this kind of dialogue.

Recommendation 8 Consider options to facilitate research ethics and privacy reviews of multi-centre, multi-jurisdiction research studies

Multi centre, multi-jurisdictional research studies should have access to a centralized research ethics review process, rather than going through research ethics in each province. This would enable more timely access to multi-provincial data sets and would greatly enhance the ability of Canadians to launch Pan-Canadian research and evaluation projects. Given the richness of the available dataset this could place Canada in a highly competitive position for international research. This is particularly true for clinical research and epidemiological studies.

Implementation of these recommendations will greatly strengthen our ability to design systems to deliver high quality care in the most effective way possible. With an aging population, increasing burden of disease and ever more costly health technologies this becomes less an option than an imperative. A nimble process for accessing and linking data both within and across provinces will place Canada in a highly competitive position for international research and will increase the extent to which research funds from other jurisdictions such as the U.S. National Institutes of Health and the European Union can be deployed in Canada.

Next Steps

1. Finalize and deliver final report to CCRA – By 01 March 2011.
2. Seek additional input from organizations identified in the report that have knowledge that would inform discussions regarding implementation, including required human and final resources and time required.
3. Seek input from interested CCRA members regarding feasibility and support for the recommendations in the final report.
4. Seek direction from CCRA in May 2011.

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APPENDIX 1 Working Group Members

David Levy, MD
President and Chief Executive Officer
BC Cancer Agency

Marcy Winget, PhD
Leader, Research and Evaluation
Community Oncology
Alberta Health Services

Craig Earle, MD
Ontario Institute for Clinical Evaluative Sciences
Cancer Care Ontario Health Services Research Program

Louise Paquet, MSc
Agent de recherche et de planification
Direction de la lutte contre le cancer
Ministère de la Santé et des Services sociaux

Louise Parker, PhD
Canadian Cancer Society (Nova Scotia) Chair in Population Cancer Research
Professor Depts Medicine and Pediatrics
Population Cancer Research Program

Janey Shin
Director, Analytic Unit
Canadian Partnership Against Cancer

APPENDIX 2   Summary of CD-Link Procedures

Application Process

An application by a Principal Investigator (PI) is submitted to the OICR/CCO HSR Program Leader for review by providing an electronic copy of a brief (approximately 5 page) proposal with the following elements:

- Rationale and objectives
- Data required and justification for each variable
- Planned analyses and planned use of the data
- Expected Products
- Describe data custodian resources for ensuring the security of the data
- Timeline
- List research staff, role, and contact information

Review Process

Program Leader:

1. The OICR/CCO HSR Program Leader reviews the proposal and if deemed to be consistent with ICES and CCO privacy policies and feasible, it will be forwarded to the Program Administrator

Program Administrator (PA):

1. The PA will distribute the proposal to the wider membership of the ICES Cancer Program for review.
2. If rejected by the Program Leader, s/he will communicate this fact and the reasons to the PI.
3. If accepted the process enters the Agreement Process.

ICES Cancer Program:

1. Review any proposal received sent by the PA at the next monthly ICES Cancer Program meeting. The purpose of the review is to
    a) ensure that the ICES and CCO privacy policies are adhered to,
    b) that the project is feasible with the cd-link data, and
    c) that the project constitutes an appropriate use of cd-link data.

The Chief Privacy Officer (CPO) and the Chief Information Security Officer (CISO) are available for consultation as needed.

Agreement Process

1. The PA will send a data use agreement (DUA), a confidentiality agreement, and a Data Creation Plan (DCP) to the PI with instructions that anyone else in the research team who will use the data for its designated purpose must sign a confidentiality agreement as well. Per ICES' policy, confidentiality agreements will need to be renewed on an annual basis. On receipt of the DCP, the analyst will review and contact the PI is any clarifications are needed

a. Creation of De-identified Data

ICES Analyst:

The ICES analyst creates the initial data sets. If any clarification is needed, the analyst will contact the PI to determine the final requirements. If any changes are made to the DCP, the analyst will e-mail the final version to the PI and send a copy to the PA for filing.

The following de-identifying steps are carried out on the initial data sets:

a) Date of birth is truncated to year of birth
b) All dates are changed to the number of days relative to the study index date, which could be the date of diagnosis of the cancer of interest or the date of death
c) Date of diagnosis in the Ontario Cancer Registry is truncated to year of diagnosis
d) No geographic information more granular than LHIN is included.
e) The ICES IKN is replaced with an identifier unique to that data release. Datasets from one data release will thus be linkable to each other, but not to any other datasets.
f) Similarly, the provider identifiers (physnum and presc_i) are replaced with an identifier unique to that data release.
g) If the CIHI variable "epi", episode of care, was requested, the first 10 characters (containing the IKN) are replaced with the dua-specific subject number.
h) Institution and facility numbers will be scrambled.
i) The following variables do not appear in any datasets for release: ikn; chartnum; ikn_a; ikn_o; key; nacrskey; regnum; regnum2; serial; id; rcc_chrt; pstlcode; fsa; cnty; dhc

The initial data set is converted to a .csv format so that it can be imported into the Privacy Analytics Risk Assessment Tool (PARAT) Software that assesses the re-identification risk of a particular data set

b. Creation of 'Risk-Reduced De-identified Data' (R2D2)

1. Once the data set is accessed on the PARAT server, the analyst selects the quasi-identifiers and the risk of re-identification is computed using the PARAT software.
2. If the risk of re-identification is > .33 the analyst works with the investigator to make any necessary changes to the variables with a goal of reducing the re-identification risk to less than .33. All data sets released by the cd-link program must have a re-identification risk ≤ .33 (at least 3 similar observations in data sets released), and preferably ≤ .2 (at least 5 similar observations in data sets released) in order to be deemed allowable to release to investigators. The ≤ .33 threshold will only be used if achieving the ≤ .2 threshold would interfere with the ability to carry out the research study.
3. Data sets that are above .33 will be further anonymized e.g., by categorizing variables (e.g., 5-year age ranges instead of 1-year), or suppressing variables for certain subjects (e.g., becomes 'unknown').

Data transmission and End of Analysis

1. The cd-link data sets will be provided to Principal Investigators on encrypted CDs by a fully tracked delivery provider (e.g., courier), or through the ICES secure SSL VPN port. The release will contain:
    - The R2D2 files, either in SAS format (preferred) or in csv format
    - A Summary report, including a brief description of each file produced
    - A more detailed variable-by-variable description of each file ("codebook")

- A summary of relevant OCR data that was not linkable to other datasets

Electronic copies of these will be retained by ICES, in a location determined by the Director, Information Management. In addition, the IKN-subject crosswalk file (which never leaves the UNIX) will also be retained, in a separate location.

2. At the 'End of Analysis' time of the DUA, the PA will contact the investigator for an update of the project's status. If necessary, the End of Analysis and End of DUA dates will be amended by submission of an amended proposal and DUA.
3. Three months before the DUA end date, the PA will send a 'Certificate of Destruction' (see schedule 2) to the PI and request that the certificate be completed, signed and returned by mail, fax, or e-mail.

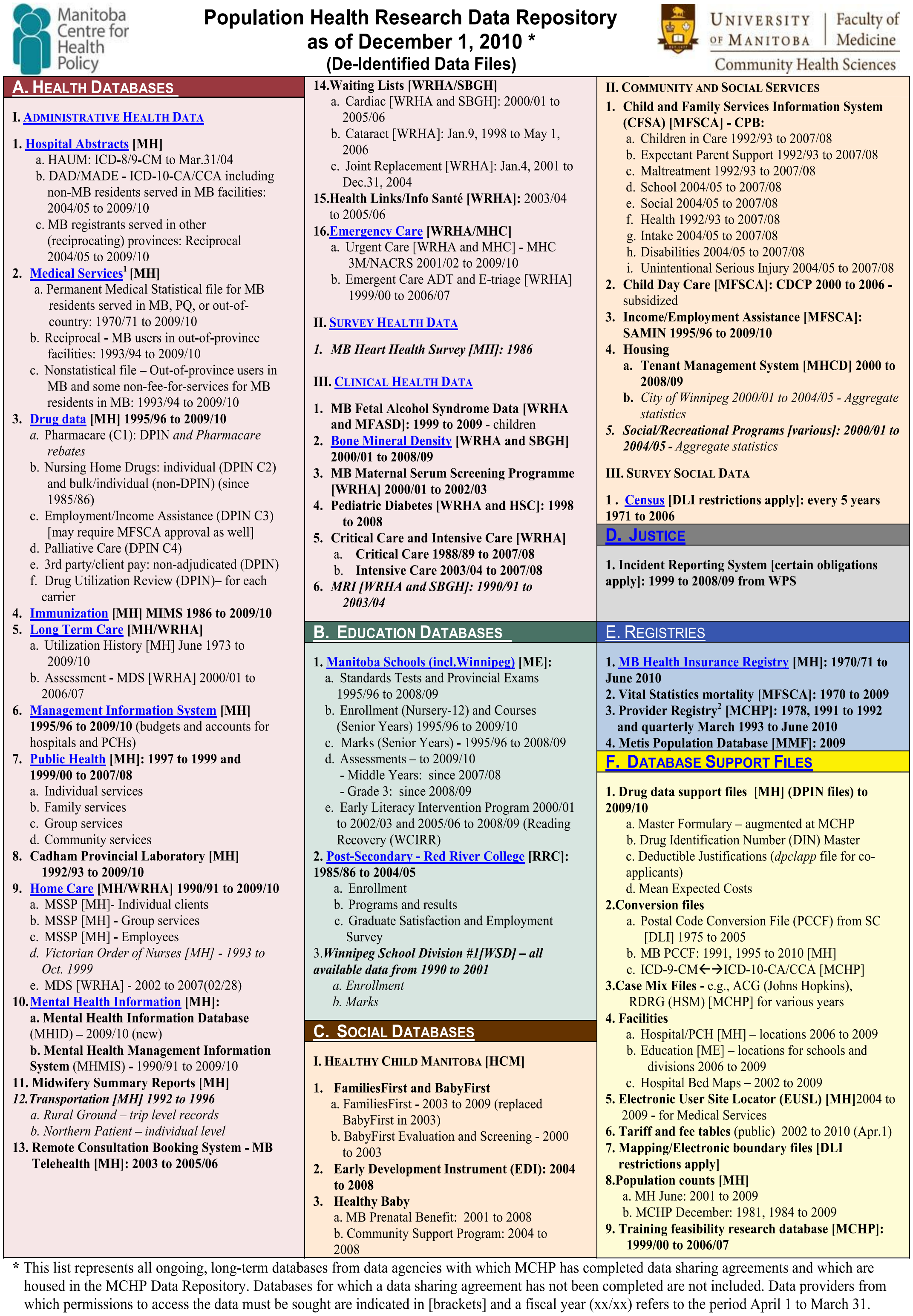
Prepublication Review
As part of the DUA, any manuscript must be submitted to the PA for review at least 45 days prior to publication.

Database	Description	Main data categories
CIHI – Discharge abstract database	These data sets contain patient-level data for acute, rehab, chronic, and day surgery institutions in Ontario. Each observation represents one case. Every record contains information about one hospital stay (DAD) or one same-day surgery stay (SDS). Deaths and sign-outs are included. http://www.ices.on.ca/file/DAD%20and%20SDS.doc	➢ ICES Key Number, anonymously linkable to other individual-level data holdings ➢ Clinical data (diagnoses, procedures, physician) ➢ Administrative data (institution/hospital number, admission category, length of stay, disposition) ➢ Data used to evaluate patient length of stay and resource consumption, as defined using case mixed group (CMG), complexity (Plx) and resource intensity weight (RIW) ➢ Patient Demographics (sex, date of birth, postal code, county and residence code)
CIHI – National Ambulatory Care Reporting System	The National Ambulatory Care Reporting System (NACRS) contains information on outpatient visits to hospital and community based ambulatory care, such as emergency departments, cancer clinics, renal dialysis clinics and others. Every record contains information about one visit to ambulatory care. http://www.ices.on.ca/file/NACRS.doc	➢ ICES Key Number, anonymously linkable to other individual-level data holdings ➢ Clinical data (diagnoses, procedures, physician) ➢ Type of ambulatory care setting ➢ Administrative data (institution number, triage level, length of stay, visit

		disposition) ➢ Data used to evaluate patient resource consumption, as defined using the Comprehensive Ambulatory Classification System (CACS) ➢ Patient Demographics (sex, date of birth, postal code, county and residence code)
Home Care Database	Captures all services provided by or coordinated by Ontario's Community Care Access Centres (CCACs). These organizations were established by the Ministry of Health and Long-Term Care to provide access to government-funded home and community services and long-term care homes. http://www.ices.on.ca/file/HCD.doc	➢ ICES Key Number, anonymously linkable to other individual-level data holdings ➢ Client ➢ Intake ➢ Assessment ➢ Admission & Discharge ➢ Diagnosis and Surgical Procedure ➢ Care Delivery
Ontario Drug Benefit Claims	The Ontario Drug Benefit (ODB) program provides drug benefits for all adults aged 65+ and those receiving social assistance in Ontario. The pharmacist submits a claim for each prescribed drug that is covered under the ODB formulary. These claims form the basis of the ODB database. Every record pertains to one drug claim dispensed under the Ontario Drug Plan. http://www.ices.on.ca/file/ODB.doc	➢ ICES Key Number, anonymously linkable to other individual-level data holdings ➢ Drug Identification Number ➢ Drug quantity ➢ Number of days supplied (can be used to compute daily dose) ➢ Cost, split into its elements ➢ Long Term Care indicator ➢ Plan that prescription falls under (such as Seniors, Trillium, Ontario Works etc.) ➢ Dispensing date, patient and prescriber identifiers (encrypted)
Ontario Health Insurance Plan Claims Database	This dataset contains claims paid for by the Ontario Health insurance Plan. The data cover all health care providers who can claim under OHIP, including physicians, groups, laboratories, and out-of-province providers. Every record contains information from one OHIP claim, such as a physician visit http://www.ices.on.ca/file/OHIP.doc	➢ ICES Key Number, anonymously linkable to other individual-level data holdings ➢ Service provided ➢ Associated diagnosis ➢ Fee paid ➢ Date of service, patient and physician identifiers (encrypted) ➢ Physician specialty

CytoBase (Cervical Screening)	Cytobase is comprised of cervical cytology data (“Pap Test” results) collected from participating community laboratories. This cervical cancer screening database contains patient, physician and laboratory information.	➢ administrative data ➢ clinical data ➢ demographic data
Ontario Breast Screening Program (OBSP)	The associated Integrated Client Management System database provides an integrated set of data for each client screened in the OBSP for the purposes of program administration, management and evaluation.	➢ administrative data ➢ clinical data ➢ demographic data
Ontario Cancer Registry Information System (OCRIS)	The OCR is a computerized database of information on all Ontario residents who have been newly diagnosed with cancer ("incidence") or who have died of cancer ("mortality"). All new cases of cancer are registered, except non-melanoma skin cancer. Note: stage has not been captured comprehensively, although it is improving rapidly. TNM stage is captured in the Regional Cancer Centers (60% of patients) and since 2009 by Collaborative Stage in community settings . As of March 31, 2010, stage capture is over 85% for the 4 major cancers (breast, lung, colorectal, prostate) and over 70% for all others.	➢ ICES Key Number, anonymously linkable to other individual-level data holdings ➢ Patient demographics ➢ Cancer diagnosis details ➢ Death information
Registered Persons Data Base (RPDB)	The RPDB provides basic demographic information about anyone who has ever received an Ontario health card number.	➢ Administrative data ➢ Demographic data

APPENDIX 3 - MANITOBA CENTRE FOR HEALTH POLICY POPULATION HEALTH RESEARCH DATA REPOSITORY



Manitoba Centre for Health Policy

Population Health Research Data Repository as of December 1, 2010 *

(De-Identified Data Files)

UNIVERSITY OF MANITOBA | Faculty of Medicine
Community Health Sciences

A. HEALTH DATABASES

I. ADMINISTRATIVE HEALTH DATA

1. **Hospital Abstracts [MH]**
   a. HAUM: ICD-8/9-CM to Mar.31/04
   b. DAD/MADE - ICD-10-CA/CCA including non-MB residents served in MB facilities: 2004/05 to 2009/10
   c. MB registrants served in other (reciprocating) provinces: Reciprocal 2004/05 to 2009/10
2. **Medical Services[1] [MH]**
   a. Permanent Medical Statistical file for MB residents served in MB, PQ, or out-of-country: 1970/71 to 2009/10
   b. Reciprocal - MB users in out-of-province facilities: 1993/94 to 2009/10
   c. Nonstatistical file – Out-of-province users in MB and some non-fee-for-services for MB residents in MB: 1993/94 to 2009/10
3. **Drug data [MH] 1995/96 to 2009/10**
   a. Pharmacare (C1): DPIN *and Pharmacare rebates*
   b. Nursing Home Drugs: individual (DPIN C2) and bulk/individual (non-DPIN) (since 1985/86)
   c. Employment/Income Assistance (DPIN C3) [may require MFSCA approval as well]
   d. Palliative Care (DPIN C4)
   e. 3rd party/client pay: non-adjudicated (DPIN)
   f. Drug Utilization Review (DPIN)– for each carrier
4. **Immunization [MH] MIMS 1986 to 2009/10**
5. **Long Term Care [MH/WRHA]**
   a. Utilization History [MH] June 1973 to 2009/10
   b. Assessment - MDS [WRHA] 2000/01 to 2006/07
6. **Management Information System [MH] 1995/96 to 2009/10** (budgets and accounts for hospitals and PCHs)
7. **Public Health [MH]: 1997 to 1999 and 1999/00 to 2007/08**
   a. Individual services
   b. Family services
   c. Group services
   d. Community services
8. **Cadham Provincial Laboratory [MH] 1992/93 to 2009/10**
9. **Home Care [MH/WRHA] 1990/91 to 2009/10**
   a. MSSP [MH]- Individual clients
   b. MSSP [MH] - Group services
   c. MSSP [MH] - Employees
   d. Victorian Order of Nurses [MH] - 1993 to Oct. 1999
   e. MDS [WRHA] - 2002 to 2007(02/28)
10. **Mental Health Information [MH]:**
    a. Mental Health Information Database (MHID) – 2009/10 (new)
    b. Mental Health Management Information System (MHMIS) **-** 1990/91 to 2009/10
11. **Midwifery Summary Reports [MH]**
12. ***Transportation [MH] 1992 to 1996***
    a. Rural Ground – trip level records
    b. Northern Patient – individual level
13. **Remote Consultation Booking System - MB Telehealth [MH]: 2003 to 2005/06**
14. **Waiting Lists [WRHA/SBGH]**
    a. Cardiac [WRHA and SBGH]: 2000/01 to 2005/06
    b. Cataract [WRHA]: Jan.9, 1998 to May 1, 2006
    c. Joint Replacement [WRHA]: Jan.4, 2001 to Dec.31, 2004
15. **Health Links/Info Santé [WRHA]:** 2003/04 to 2005/06
16. **Emergency Care [WRHA/MHC]**
    a. Urgent Care [WRHA and MHC] - MHC 3M/NACRS 2001/02 to 2009/10
    b. Emergent Care ADT and E-triage [WRHA] 1999/00 to 2006/07

II. SURVEY HEALTH DATA

1. ***MB Heart Health Survey [MH]: 1986***

III. CLINICAL HEALTH DATA

1. **MB Fetal Alcohol Syndrome Data [WRHA and MFASD]: 1999 to 2009** - children
2. **Bone Mineral Density [WRHA and SBGH] 2000/01 to 2008/09**
3. **MB Maternal Serum Screening Programme [WRHA] 2000/01 to 2002/03**
4. **Pediatric Diabetes [WRHA and HSC]: 1998 to 2008**
5. **Critical Care and Intensive Care [WRHA]**
   a. **Critical Care 1988/89 to 2007/08**
   b. **Intensive Care 2003/04 to 2007/08**
6. ***MRI [WRHA and SBGH]: 1990/91 to 2003/04***

B. EDUCATION DATABASES

1. **Manitoba Schools (incl.Winnipeg) [ME]:**
   a. Standards Tests and Provincial Exams 1995/96 to 2008/09
   b. Enrollment (Nursery-12) and Courses (Senior Years) 1995/96 to 2009/10
   c. Marks (Senior Years) - 1995/96 to 2008/09
   d. Assessments – to 2009/10
      - Middle Years: since 2007/08
      - Grade 3: since 2008/09
   e. Early Literacy Intervention Program 2000/01 to 2002/03 and 2005/06 to 2008/09 (Reading Recovery (WCIRR)
2. **Post-Secondary - Red River College [RRC]: 1985/86 to 2004/05**
   a. Enrollment
   b. Programs and results
   c. Graduate Satisfaction and Employment Survey
3. ***Winnipeg School Division #1[WSD] – all available data from 1990 to 2001***
   a. Enrollment
   b. Marks

C. SOCIAL DATABASES

I. HEALTHY CHILD MANITOBA [HCM]

1. **FamiliesFirst and BabyFirst**
   a. FamiliesFirst - 2003 to 2009 (replaced BabyFirst in 2003)
   b. BabyFirst Evaluation and Screening - 2000 to 2003
2. **Early Development Instrument (EDI): 2004 to 2008**
3. **Healthy Baby**
   a. MB Prenatal Benefit: 2001 to 2008
   b. Community Support Program: 2004 to 2008

II. COMMUNITY AND SOCIAL SERVICES

1. **Child and Family Services Information System (CFSA) [MFSCA] - CPB:**
   a. Children in Care 1992/93 to 2007/08
   b. Expectant Parent Support 1992/93 to 2007/08
   c. Maltreatment 1992/93 to 2007/08
   d. School 2004/05 to 2007/08
   e. Social 2004/05 to 2007/08
   f. Health 1992/93 to 2007/08
   g. Intake 2004/05 to 2007/08
   h. Disabilities 2004/05 to 2007/08
   i. Unintentional Serious Injury 2004/05 to 2007/08
2. **Child Day Care [MFSCA]: CDCP 2000 to 2006 -** subsidized
3. **Income/Employment Assistance [MFSCA]: SAMIN 1995/96 to 2009/10**
4. **Housing**
   a. Tenant Management System [MHCD] 2000 to 2008/09
   b. *City of Winnipeg 2000/01 to 2004/05 - Aggregate statistics*
5. ***Social/Recreational Programs [various]: 2000/01 to 2004/05 -*** *Aggregate statistics*

III. SURVEY SOCIAL DATA

1 . **Census [DLI restrictions apply]: every 5 years 1971 to 2006**

D. JUSTICE

1. Incident Reporting System [certain obligations apply]: 1999 to 2008/09 from WPS

E. REGISTRIES

1. MB Health Insurance Registry [MH]: 1970/71 to June 2010
2. Vital Statistics mortality [MFSCA]: 1970 to 2009
3. Provider Registry[2] [MCHP]: 1978, 1991 to 1992 and quarterly March 1993 to June 2010
4. Metis Population Database [MMF]: 2009

F. DATABASE SUPPORT FILES

1. Drug data support files [MH] (DPIN files) to 2009/10
   a. Master Formulary – augmented at MCHP
   b. Drug Identification Number (DIN) Master
   c. Deductible Justifications (*dpclapp* file for co-applicants)
   d. Mean Expected Costs
2.Conversion files
   a. Postal Code Conversion File (PCCF) from SC [DLI] 1975 to 2005
   b. MB PCCF: 1991, 1995 to 2010 [MH]
   c. ICD-9-CM←→ICD-10-CA/CCA [MCHP]
3.Case Mix Files - e.g., ACG (Johns Hopkins), RDRG (HSM) [MCHP] for various years
4. Facilities
   a. Hospital/PCH [MH] – locations 2006 to 2009
   b. Education [ME] – locations for schools and divisions 2006 to 2009
   c. Hospital Bed Maps – 2002 to 2009
5. Electronic User Site Locator (EUSL) [MH]2004 to 2009 - for Medical Services
6. Tariff and fee tables (public) 2002 to 2010 (Apr.1)
7. Mapping/Electronic boundary files [DLI restrictions apply]
8.Population counts [MH]
   a. MH June: 2001 to 2009
   b. MCHP December: 1981, 1984 to 2009
9. Training feasibility research database [MCHP]: 1999/00 to 2006/07

* This list represents all ongoing, long-term databases from data agencies with which MCHP has completed data sharing agreements and which are housed in the MCHP Data Repository. Databases for which a data sharing agreement has not been completed are not included. Data providers from which permissions to access the data must be sought are indicated in [brackets] and a fiscal year (xx/xx) refers to the period April 1 to March 31.

Databases available for research but no longer updated are shown in italics. Links are included to descriptions, where developed, of the databases.

[1] Is noted as *Medical Claims (Physician Billings)* in the HIPC application form

[2] Augmented version of the *Physician Resource File* referred to in the HIPC application form. Generally required for obtaining information about provider characteristics other than specialty (which is available in the Medical Services data).

97 data files are grouped in this list into 3 levels:

1) **Domains -** broad conceptual categories, reflecting internal organization of data files into libraries
2) **Databases (bolded)** (N=49) - groupings of data into conceptual analytical entities meaningful to researchers and typically used for carrying ou studies.
3) **Sub-categories** (another N=48) - groupings that further distinguish significant differences in content and/or data sources within database groupings.

ACRONYMS

ADT	Admissions, Discharges, and Transfers
CCHS	Canadian Community Health Survey
CFSA	Child and Family Services Applications consists of two databases – CFSIS (a-f, h-i) and Intake (g)
CFSIS	Child and Family Services Information System
CPB	Child Protection Branch
DAD	Discharge Abstract Data
DLI	Data Liberation Initiative
DPIN	Drug Program Information Network
EIA	Employment and Income Assistance
HAUM	Hospital Abstracts User Manual
HSC	Health Sciences Centre
HSM	Health Systems Management
ICAB	Instruction, Curriculum and Assessment Branch
ICD	International Classification of Diseases
MADE	Manitoba Abstract Data Elements
MDS	Minimum Data Set
MFASD	Manitoba Fetal Alcohol Syndrome Data (formerly Clinic for Alcohol and Drug Exposed Children)
ME	Manitoba Education
MFSCA	Manitoba Family Services and Consumer Affairs
MH	Manitoba Health
MHCD	Manitoba Housing and Community Development
MIMS	Manitoba Immunization Monitoring System
MHC	Misericordia Health Centre
MMF	Manitoba Metis Federation
MRI	Magnetic Resonance Imaging
MSSP	Manitoba Support Services Payroll
NACRS	National Ambulatory Care Reporting System
NPHS	National Population Health Survey
PCCF	Postal Code Conversion File
SAMIN	Social Assistance Management Information Network
SBGH	St. Boniface General Hospital
SC	Statistics Canada
STS	Systems and Technology Services
WCIRR	Western Canada Institute for Reading Recovery
WPS	Winnipeg Police Service
WRHA	Winnipeg Regional Health Authority

APPENDIX 4 - POPULATION HEALTH RESEARCH DATA REPOSITORY EXAMPLE, MANITOBA

Population Health Research Data Repository

- Administrative Health Data: Drug Database -

Database Name	**DRUG DATA**
Source Agency	Manitoba Health
Type	Administrative health
Purpose	To facilitate payment administration by the Provincial Drug Programs (PDP) Unit for eligible drug costs in provincially funded programs within Manitoba Health. This is managed through the interface provided by the Drug Program Information Network (DPIN).
Scope	• All Manitoba residents (including Registered First Nations) regardless of insurance coverage or final payer. • All prescriptions with a Drug Identification Number (DIN) or Product Information Number (PIN) issued to Manitoba residents through the following programs for adjudication:Pharmacare, Personal Care Home, Employment and Income Assistance, and Palliative Care. Non-adjudicated prescriptions represent a fifth category of transactions submitted for screening of possible inappropriate use before dispensation. • Services not captured in the drug database include hospital pharmacies for Manitoba residents, nursing stations, ward stock, and outpatient visits at CancerCare Manitoba. As well, about 20% of dispensed prescriptions to Registered First Nations (RFN)were not captured prior to 2006 (representing about 1% of all prescriptions dispensed outside hospitals). Also not captured are about 25% of personal care homes (those which obtain drugs through a hospital pharmacy) (Doupe et al., 2006)
Data Collection Method	An online point-of-sale system, DPIN connects - in real time - Manitoba Health and all pharmacies in Manitoba to a central database maintained by Manitoba Health. The DPIN system generates complete drug profiles for each client including all transactions at the point of distribution.
Size	Approximately 12 million transactions in total annually for all programs (carriers), with about 40 data elements. Another approximately 3 million records are processed annually

	for nonadjudicated claims (associated with about 20 data elements).
Data Level	Transactions and claims
Data Years	Fiscal 1995/96 to present for DPIN pharmacare, for pre-DPIN pharmacare 1973 to 1995. Nursing home drugs since 1985/86.
Data Highlights	• **Prescription information:** e.g., drug, dosage, and prescription date. (Non-prescription drugs or over-the-counter (OTC) drug products possessing a DIN allowed by the drug plan may also be present.) • **Prescriptions identified as potential drug utilization problems:** the Drug Utilization Review Service for adjudicated claims generates Drug Utilization Response Codes such as dose outside acceptable guidelines, drug interactions, duplication, double-doctoring, maximim accepted ingredient price. • **Non-adjudicated claims** - approximately 15% of all prescriptions • **Ancillary programs and non-drug products**
Access Requirements	• **Government of Manitoba -** Health Information Privacy Committee (HIPC) • **University of Manitoba** - Research Ethics Board (REB) The process for arranging access to the MCHP Data Repository is outlined in the Applying for Access section of the Research Resources.
More Information	Drug database guide - includes more information about this database in 4 sections: 1. Overview - includes more details on e.g.,DPIN programs; data validation studies. 2. Data Strengths and Tools - includes links to MCHP concepts, studies that have used the DPIN data, and other drug data resources. 3. Data Cautions - includes sections on data completeness and other issues/recommendations. 4. Study Examples - four example approaches to carrying out drug studies.
Last updated December 18, 2009	

Manitoba Centre for Health Policy
Community Health Sciences, Faculty of Medicine, 408-727 McDermot Ave.
University of Manitoba Bannatyne Campus, Winnipeg, MB R3E 3P5 Canada
Office: (204) 789-3819 Fax: (204) 789-3910
info@cpe.umanitoba.ca
http://umanitoba.ca/

APPENDIX 5 BREAST CANCER SCREENING DATABASE

	Name of Database	Custodian of Database	DATA ACCESS	Comments
NL	Breast Screening Database	Eastern Health Cancer Care Program	Internal access within Cancer Agency informal policy, requires email requesting access	Data has not been linked to cancer registry
NS	Nova Scotia Breast Screening Program	NS Breast Screening Program on behalf NS Dept of Health	Formal access process through NS Dept of Health	Data has not been linked to cancer registry
PE	PEI Breast Screening Program	Diagnostic Imaging Program Health PEI	Data access is through the Breast Screening Program Coordinator, who may need to coordinate with IT shared services for any kind of data reporting or linkage.	GE system does not allow linkage with other databases. Manual process: supply stage data which is then manually entered into the screening program.
NB	NB Cancer Network Policy	New Brunswick Cancer Network	Internal access within Cancer Agency Informal policy in draft form. Request is assessed by Chief Privacy Officer, then send to exec. NBCN	Turnaround time for data access can be long
ON	Ontario Breast Screening Program	Cancer Care Ontario	There is a formal access policy. Written request (describing rationale/objectives, data elements, methods, knowledge transfer, security arrangements, timelines, research staff) for data access is considered by Ontario Institute for Cancer Research/Cancer Care Ontario. Request describes rationale/objectives, data elements, methods, knowledge transfer, security arrangements, timelines, and research staff. Guiding Institute for Clinical Evaluative Sciences and Cancer Care Ontario privacy policies.	Data linked via "cd-link" initiative
QU	Programme quebecois de depistage du cancer du sein ISI-PQDCS)	Institut national de sante publique	Written request to Ministry of Health describing objectives, sample size, methods, security arrangements retention and disposal of the data	Linked but not internal to cancer registry
MB	Manitoba Breast Screening Database	Cancer Care Manitoba	Internal database	Linkage conducted within the cancer registry
SK	Screening Program for Breast Cancer	Saskatchewan Cancer Agency	Internal database	Linkage conducted within the cancer registry
AB	Alberta Breast Screening	AHS – Population Health	Written Data access policy Privacy Impact Assessment and Research Ethics Board Approval required	Policies are very protective, Privacy Impact Assessment is required which creates gap between government, custodians and researchers
BC	Screening Mammography Program of BC (SMPBC)	BC Cancer Agency	There is a written policy in place around all electronic data. Request form submitted to the screening program leader and approved by Head of the screening programs. BCCA governed by Freedom of Information and Privacy Protection Act, policies for electronic data include usage, storage, retrieval, retention/disposal and security of data	

APPENDIX 6 CERVICAL CANCER SCREENING DATABASES

	Name of Database	Custodian of Database	DATA ACCESS	COMMENTS
NL	Cytology Registry	Eastern Health Cancer Care Program	Internal access with informal policy	No attempts have been made to link with cancer registry
NS	Cervical Screening Registry and Colposcopy Registry	Nova Scotia Cervical Cancer Prevention Program, CCNS	Internal access with informal policy Written internal request for operational purposes	Linkage conducted within the cancer registry
PE	The Cervical Screening Program is run through the provincial laboratory. The database is maintained by the lab and the custodian is one of the Pathologists in the lab. We have not requested linkage but do receive all positive cervical reports automatically in the cancer registry and there is a link to Histology. The DB is an oracle DB maintained in Cerner Millenium. Any linkages would require support of ITSS			
NB	NO DATABASE			
ON	Cervical CytoBase	Cancer Care Ontario	Written request to Ontario Institute for Cancer Research/Cancer Care Ontario describing rationale/objectives, data elements, methods, knowledge transfer, security arrangements, timelines, research staff. Must meet with Institute for Clinical Evaluative Sciences and Cancer Care Ontario privacy policies.	Data linked to cancer registry via "cd-link" initiative
QU	IN DEVELOPMENT			
MB	Manitoba Cervical Cancer Database	Cancer Care Manitoba	Internal access with informal policy REB required if request is research related. Personal Health Information Act guidelines must be followed.	Linkage has been conducted within the cancer registry (operational & research purposes)
SK	Prevention Program for Cervical Cancer	Saskatchewan Cancer Agency	Internal Access	Linkage has been conducted within the cancer registry
AB	Alberta Cervical Cancer Screening	AHS – Population Health	Written access policy Requires Privacy Impact Assessment and Research Ethics Board approval	Policies are very protective of privacy, All data access requires privacy impact assessment. This proves a challenge to research.
BC	Cervical Cancer Screening Program (CCSP)	BC Cancer Agency	Yes, internal Yes, written policy in place around electronic data Effective BCCA governed by Freedom of Information and Privacy Protection Act, policies for electronic data include usage, storage, retrieval, retention/disposal and security of data	Linkage has been conducted within the cancer registry

APPENDIX 7 COLORECTAL CANCER SCREENING DATABASES

	Name of Database	Custodian of Database	DATA ACCESS	COMMENTS
NL	IN DEVELOPMENT			
NS	In development. Screening not yet population based	Nova Scotia Colorectal Prevention Program, CCNS CASPER	Internal Access Informal access policy Written request, often for operational purposes	Not linked with cancer registry
PE	Currently an Access database. Access falls to Health PEI			
NB	NO DATABASE			
ON	IN DEVELOPMENT			
QU	IN DEVELOPMENT			
MB	IN DEVELOPMENT			
SK	Screening Program for Colorectal Cancer	Saskatchewan Cancer Agency	No.	Linkage has been conducted within the cancer registry
AB	Alberta Colorectal Screening	AHS – Population Health	Written Policy for data access	
BC	IN DEVELOPMENT Coloncheck (for residents of Penticon and Powell River)	BC Cancer Agency	Written policy in place around electronic data BCCA governed by Freedom of Information and Privacy Protection Act, policies for electronic data include usage,storage,retrieval,retention/disposal and security of data	Linkage has been conducted within the cancer registry

APPENDIX 8 - AMBULATORY CARE DATABASES

	Comments on access to Ambulatory Care Database
NL	Databases are held by each health region and are accessed through government and partner agency Health Regions Each Region has its own policies for data access
NS	Access in through application to government department agency aligned with written policy Yes, written policy
PE	There is only one acute care hospital that submits data to the National Ambulatory Care Reporting System- this hospital reports to NACRS for ER visits only. No linkage has been requested. ITSS would be involved in any linkage requests as well as the Medical Records Manager of the Hospital involved.
NB	Hospital Information System POC – Margaret Eastwood Prov. MIS ICES Key Number, anonymously linkable to other individual-level data holdings. • Clinical Data (diagnosis, procedures, physician) • Type of Ambulatory care setting •Administrative data (institution number, triage level, length of stay, visit disposition) • Data used to evaluate patient resource consumption, as defined using the Comprehensive Ambulatory Classification System (CACS) • Patient demographics (sex •, date of birth, postal code, country and residence code
ON	Ontario Ministry of Health National Ambulatory Care Reporting System Written request to Ontario Institute for Cancer Research/Cancer Care Ontario describing rationale/objectives, data elements, methods, knowledge transfer, security arrangements, timelines, research staff. Must meet with Institute for Clinical Evaluative Sciences and Cancer Care Ontario privacy policies Data linked via "cd-link" initiative
QU	Not available
MB	Access is through government department/ partner agency. There is written policy Data sharing agreement (HIPC) and Tri-Act Agreements (Cancer Care Manitoba Act, Manitoba Public Health Act, Manitoba Health Act) Yes, linkage conducted within the cancer registry Multi-stage process involving extraction of administrative data from Manitoba Health and linkage to data extracted from cancer registry by Cancer Care Manitoba staff. Written request describing investigators, purpose, data elements, level of intrusion, data security, knowledge transfer
SK	Not available for whole province One hospital in SK started reporting to Ntl Amb Care Reporting System in 2010 Yes, internal
AB	Alberta Ambulatory Care Classification System Alberta Health and Wellness Yes, through government department/partner agency
BC	The National Ambulatory Care Reporting System (NACRS) BC Ministry of Health CIHI – Canadian Institute for Health Information Yes, internal access Alberta H&W does not have enough resources to respond to data requests

APPENDIX 9 CLINICAL CARE AND TREATMENT DATABASES

	Name of Database	Custodian of Database	DATA ACCESS	COMMENTS
NL	IN DEVELOPMENT Cancer Treatment/Toxicities Database	Cancer Care Program – Eastern Health		
NS	Oncology Patient Information System (OPIS)	Cancer Care Nova Scotia	Internal data access Policy for data access is in development	Linkage has been conducted within the cancer registry
PE	PEI Cancer Registry is the population based db for cancer incidence. ARIA by Varian	Legal Authority to Collect cancer comes from the Chief Health Officer, but the Cancer Registry is part of Health PEI. The Manager of the Cancer Registry is the custodian and reviews and responds to all requests for data.	Internal data access Policy for data access is in development. Requests for data are also reviewed by the privacy officer	The cancer registry system- Oncolog will have the capability to accept treatment data from the ARIA system. ARIA by Varian is the clinical database where radiation treatment and some medical oncology workload data is collected.
NB	Cancer Treatment Access Repository	Hospital Information System – Dept.of Health NB	Informal process for access by epidemiologist only	Turnaround Time can be long
ON	Ontario Cancer Registry Information System	Cancer Care Ontario	Processes as for all databases e.g., see Ambulatory Care data set Table x	Data linked via "cd-link" initiative
QU	NOT AVAILABLE		N/A	
MB	ARIA by Varian Medical Systems	Cancer Care Manitoba	Yes, internal.	Linkage completed by epidemiology and cancer registry staff. Excludes Manitoba Health
SK	ARIA by Varian Medical Systems	Saskatchewan Cancer Agency	Yes, internal.	IT shortages & lack of process for data request. No identified manager Yes

AB	ARIA by Varian Medical Systems	AHS – Cancer Care	Yes, internal process for data access.	
BC	Cancer Agency Information System (CAIS)	BC Cancer Agency	Internal data access with written policy in place around electronic data internal	Linkage conducted within the cancer registry

APPENDIX 10 DEMOGRAPHICS AND POPULATION DATABASES

	Name of Database	Custodian of Database	Access to the database?	Comments
NL	MCP	Department of Health and Community Services	No	
NS	Medical Insurances Registration (MSI Database	NS Dept of Health, managed by Medavie Blue Cross	Internal linkage access via Long standing agreement for operational purposes	Linkage conducted within the cancer registry
PE	Client Registry	Health PEI	Internal access via Informal Policy Written request IT Shared Services	Issue with IT resources for linking and analyzing data
NB	Medicare	NB Dept. of Health	Informal Policy Written request	Must work through database analyst Time issue in accessing data
ON	Registered Persons Data Base	Ontario Ministry of Health and Long-Term Care	Written request to Ontario Institute for Cancer Research/Cancer Care Ontario describing rationale/objectives, data elements, methods, knowledge transfer, security arrangements, timelines, research staff. Must meet with Institute for Clinical Evaluative Sciences and Cancer Care Ontario privacy policies.	Data linked via "cd-link" initiative
QU	Fichier d'inscription des personnes assurees	Regie de l'assurance maladie du Quebec	Written request to Commission d'accès à l'information describing objectives, sample size, methods, security arrangements retention and disposal of the data.	Linkage was conducted but through an outside agency
MB	Manitoba Health Insurance Database	Manitoba Health	Yes, internal Data sharing agreement (tri-act agreement), big 'R' agreement (non-op.) Written request describing investigators, purpose, data elements, level of intrusion, data security, knowledge transfer	Yes, linkage was conducted within the cancer registry in partnership w. Man Health Health Information Privacy Committee clear and works well
SK	Person Health Registry System	Saskatchewan Ministry of Health	Yes, through government department/ partner agency Data sharing agreement (HIPC) and Tri-Act Agreements (Cancer Care Manitoba Act, Manitoba Public Health Act, Manitoba Health Act) Ministry of Health HISC	Linkage is conducted within the cancer registry
AB	Provincial Client Registry	Alberta Health and Wellness	Yes, Internal, monthly updates Data Disclosure Guidelines. Request includes purpose of research, investigators, study population, methods, and consent forms.	Very protective, privacy impact assessment for everything, problem b/c creates gap with gov. custodians and researchers. Linkage is conducted within the cancer registry
BC	Electronic Master Point Index (EMPI)	BC Cancer Agency	Internal access via written policy in place around electronic data	Linkage is conducted within the cancer registry

APPENDIX 11: DISCHARGE ABSTRACT DATABASES

	Name of Database	Custodian of Database	Access to this Database	Comments
NL	Hospital Discharge Abstract Database	Newfoundland & Labrador Centre for Health Information		
NS	Discharge Abstract Database	Department of Health, maintained by CIHI	Yes, internal informal policy Written request, often for operational purposes	Linkage is conducted within the cancer registry Privacy impact assessment can take a long time. Limited resources identified as significant factor.
PE	Discharge Database	Medical records managers (IT Shared Services)		Yes, linkage was conducted within the cancer registry IT resources have been difficult to maintain in the group responsible for reporting and linkages
NB	Accountability & Health Information Mgmt.			Waiting is the only issue
ON	Discharge Abstract Database	CIHI	Written request to Ontario Institute for Cancer Research/Cancer Care Ontario describing rationale/objectives, data elements, methods, knowledge, transfer, security arrangements, timelines, research staff. Must meet with Institute for Clinical Evaluative Sciences and Cancer Care Ontario privacy policies.	Data linked via "cd-link" initiative
QU	Maintenance et exploitation des donnes pour l'etude de la clientele hospitaliere (Med-Echo)	Ministere de la sante et des services sociaux	Written request to Commission d'accès à l'information describing objectives, sample size, methods, security arrangements retention and disposal of the data.	Linkage is conducted within the cancer registry
MB	Hospital Abstract Database	Manitoba Health	Internal access for operational purposes	Linkage is conducted within the cancer registry
SK	Discharge Abstract Database (DAD)-	Ministry of Health gets a monthly cut of data from CIHI	Internal access	
AB	Discharge Abstract Database (DAD)	Alberta Health & Wellness	There is written policy for data access Access through government department/partner agency	Alberta H&W does not have enough resources to respond to data requests. AHS is in the process of developing a data repository that links and makes accessible administrative health data and currently has the DAD. These data are currently available to researchers within AHS.
BC	Discharge Abstract Database (DAD)	CIHI – at provincial level	For Aggregated data there is a data use agreement between CIHI and BC Provincial Health Services Authority (PHSA).	

APPENDIX 12 HPV IMMUNIZATION DATABASES

	Name of Database	Custodian of Database	ACCESS	COMMENTS
NL	HPV Immunization Database	Department of Health	Cancer Registry/agency does not have access	
NS	School based immunizations Database	Dept Health Protection and Promotion	Cancer registry/agency does not have access	
PE	Integrated Systems Management (ISM) Custodian is Public Health Nursing. Access has not been requested.			
NB	No Database			
ON	No Database			
QU	I-CLSC, Vaxin or Logivac Databases	Direction de la protection de la sante publique, ministere de la Sante et des Services sociaux	Written request to Commission d'accès à l'information describing objectives, sample size, methods, security arrangements retention and disposal of the data.	
MB	Man. Immunization Monitoring Database	Manitoba Health	Access is through government department/partner agency written policy HIP-C Data sharing agreement (HIPC) and Tri-Act Agreements (Cancer Care Manitoba Act, Manitoba Public Health Act, Manitoba Health Act) Written request describing investigators, purpose, data elements, level of intrusion, data security, knowledge transfer Health Information Privacy Committee clear and works well	Linkage has been conducted through an outside agency – HPV Vaccine Surveillance
SK	Saskatchewan Immunization Management System	The health regions.	In order for the Ministry to access the data the research project has to be approved by a committee. Does not include immunizations delivered on a reserve	
AB	No Database			
BC	IN DEVELOPMENT HPV Focal Study	BC Cancer Agency		

APPENDIX 13 - HOME CARE DATABASES

	Name of Database	Custodian of Database	ACCESS	COMMENTS
NL	CRMS is community-based DB for appt scheduling Semi-population based	Eastern Health Cancer Care Program	Has not been requested	
NS	SEAscape	Department of Health	Has not been requested	
PE	Integrated Systems Management	Department of Health	Has not been requested	
NB	No			
ON	Home Care Database	Institute for Clinical and Evaluative Sciences	Written request to Ontario Institute for Cancer Research/Cancer Care Ontario describing rationale/objectives, data elements, methods, knowledge transfer, security arrangements, timelines, research staff. Must meet with Institute for Clinical Evaluative Sciences and Cancer Care Ontario privacy policies.	Data linked via "cd-link" initiative
QU				
MB	Man. Health Homecare Database	Manitoba Health		
SK	Home Care Data Mart	Health regions submit data to the Ministry of Health who collects it into a data mart	Has not been requested	
AB	Yes (previously in two of largest regions, now unsure)	The Health Regions i.e. Capital Health	Access, through government department/partner agency Unsure if it is currently available. Had been through government department/partner agency	

APPENDIX 14 PHARMACY/ PHARMACARE DATABASES

	Name of Database	Custodian of Database	ACCESS	COMMENTS
NL	Pharmacy Network	NLCHI	Just launched and in process of becoming population-based	
NS	Pharmacare	Dept of Health		Has not been linked NS's public drug insurance program that assists NS residents in paying for eligible prescription drugs and designated medical supplies. Only includes prescription drugs paid for under the PharmaCare program so is a subset of Rx issued in NS.
PE	IN DEVELOPMENT			
NB	NOT AVAILABLE			
ON	Ontario Drug Benefits Coverage	Ontario Ministry of Health and Long-Term Care	Written request following same process see Ambulatory Care	Data linked via "cd-link" initiative The Ontario Drug Benefit (ODB) program provides drug benefits for all adults aged 65+ and those receiving social assistance in Ontario. The pharmacist submits a claim for each prescribed drug that is covered under the ODB formulary. These claims form the basis of the ODB database. Every record pertains to one drug claim dispensed under the Ontario Drug Plan ICES key number, anonymously linkable to other individual-level data holdings •Drug Identification Number •Drug quantity •Number of days supplied (Can be used to compute daily dose) •Cost, split into its elements •Long term care indicator •Plan that prescription falls under (such as Seniors, Trillium, Ontario Works, etc) •Dispensing date, patient and prescriber identifiers (encrypted)
QU	Fichier des services pharmaceutiques payes pour le compte des personnes assurees (regime general d'assurance medicicaments)	Regie de l'assurance maladie du Québec	Written request to Ministry of Health describing objectives,sample size,methods,security arrangementsretention and disposal of the data	Written request to Commission d'accès à l'information describing objectives, sample size, methods, security arrangements retention and disposal of the data Has not been linked
MB	Drug Program Information Network	Manitoba Health	Yes, internal Written request describing investigators, purpose, data elements, level of intrusion, data security, knowledge transfer Data sharing agreement (HIPC) and Tri-Act Agreements (Cancer Care Manitoba Act, Manitoba Public Health Act, Manitoba	Yes, linkage was conducted within the cancer registry Health Information Privacy Committee clear and works well

			Health Act)	
SK	Pharmaceutical Information Program	Saskatchewan Health	No Access	
AB	Pharmacy Data – Alberta Blue Cross	Alberta Health and Wellness	Access through government department/partner agency	Very protective, privacy impact assessment for everything, problem b/c creates gap with gov. custodians and researchers Alberta H&W does not have enough resources to respond to data requests Information about prescription drugs, prescribing information, ambulance, prosthetics/orthotics and palliative care services for those Albertans that Alberta Health and Wellness pays Alberta Blue Cross (ABC) premiums (primarily senior citizens)
BC	Pharmacy (external OSC AR)	BCCA	Yes, written policy in place around electronic data	Drugs dispensed externally Links the network of all community hospitals across the province dispensing cancer/oncology drugs. The database includes information on demographics, utilization, costs etc
	Pharmacy (in house Medicare WoRX)	BCCA		A database of drugs prescribed to referred patients by BCCA pharmacists Serves the operational needs of the Systemic therapy program.

APPENDIX 15 - REIMBURSEMENT DATABASES

	Name of Database	Custodian of Database	ACCESS	COMMENTS
NL	MCP	Department of Health	Not requested	
NS	NS Medical Insurance Plan Payment Information File (MSI)	Department of Health	Access is through government department/partner agency Informal policy Access is via Written request, often for operational purposes	Has not been linked Privacy impact assessment can take a long time, IT resources limited
PE	Integrated Claims System	Department of Health	Access is through government department/partner agency. IT Shared Services Facilitates linkage	Yes, the linkage was conducted through an outside agency
NB	Medicare	Department of Health	Access in Internal Must work through database analyst	Time issue in accessing this database
ON	Ontario Health Insurance Plan Claims Database	ICES	N/A	Data linked via "cd-link" initiative
QU	Fichier des services payes pour le compte des personnes assurees	Regie de l'assurance du Quebec	Access is through government department/partner agency Commission d'acces a l'information, RAMQ	N/A
MB	Manitoba Health Physician Claims Database	Manitoba Health	Internal access Data sharing agreement (HIPC) and Tri-Act Agreements (Cancer Care Manitoba Act, Manitoba Public Health Act, Manitoba Health Act) Written request describing investigators, purpose, data elements, level of intrusion, data security, knowledge transfer	Linkage conducted within the cancer registry Health Information Privacy Committee clear and works well
SK	Physician Claims System	Ministry of Health	Does not have access	
AB	Physician Claims Database	Alberta Health & Wellness	ACCESS is through government department/partner agency Data Disclosure Guidelines. Request includes purpose of research, investigators, study population,methods,consent forms	Alberta H&W does not have enough resources to respond to data requests AHS is in the process of developing a data repository that links and makes accessible administrative health data. The Physician Claims data is expected to be added sometime in 2011.

BC	Medical Services Plan (MSP)	Ministry of Health	Does not have access	

APPENDIX 16 SURGICAL ONCOLOGY DATABASE

There are no provincial surgical oncology databases in Canada though there is some data available from Nova Scotia where there have been pilot/preliminary studies around colorectal cancer surgery and Alberta where there is some voluntary surgical reporting. Quebec is doing some development work in this area.

APPENDIX 17 TUMOUR BANK DATABASE

There are provincial level tumour banks in Ontario, BC, Manitoba and Quebec which are all part of the Canadian Tumour Respository Network (CTRNET).

The Canadian Tumour Repository Network was formed in 2004 with the financial assistance of the Institute for Cancer Research (ICR) of the Canadian Institutes of Health Research (CIHR) in collaboration with the Canadian Association of Provincial Cancer Agencies (CAPCA) to foster studies into the determinants of cancer, to better understand cancer prevention and early detection, and to improve the predication of drug response and the identification of new drug targets. CTRNet operates as a not-for-profit consortium of leading provincial tumour banks and programs that furthers Canadian health research. CTRNet provides interested researchers with a streamlined process to obtain quality human tissue and human tissue products from member tumour banks. The tumour bank databases typically hold demographic, clinical, diagnostic and outcome data. http://www.ctrnet.ca/about

The CTRNet operates under an agreed set of Standard Operating Procedures for sample collection and storage and an agreed set of policies around data and sample access which are published on their website. http://www.ctrnet.ca/policies.

The remaining provinces may have small investigator driven tumour banks but these are not typically linked to the cancer registries.

APPENDIX 18 VITAL STATISTICS DATABASES

	Name of Database	Custodian of Database	Does the Cancer Registry have access to this database ?	COMMENTS
NL	Vital Statistics	Government of Newfoundland/Labrador	Access is through government department/agency	No attempts have been made to link the data at provincial level
NS	Vital Statistics	Service Nova Scotia & Municipal Relations	Internal linkage	Access is restricted to event of death and cause only when cancer related Linkage was conducted within the cancer registry
PE	Director of Vital Stats	Health PEI	No direct access	Access is restricted to cancer-related deaths
NB	N/A	Service NB	N/A	
ON	N/A	N/A	N/A	
QU	N/A	N/A	Direct link	Sometimes experience a delay so data not as current as it could be Causes delays with timelines
MB	Man. Vital Stats	Manitoba Health	Access is through the government department/partner agency	Must have separate agreement between consumer and corporate affairs. Agreements can take a long time. Operational data sent immediately. Get event but not cause of death. Linkage was conducted within the cancer registry
SK	Vital Statistics Registry	Information Services Corp. (ISC)	Yes, through government department/partner agency	Linkage was conducted within the cancer registry
AB	Alberta Vital Statistics	Government of Alberta	Alberta Vital Statistics sends the Registry a electronic file each month	Linkage has been conducted within the cancer registry
BC	Vital Statistics Information System (VISION)	Ministry of Health	Through government department/partner agency	

APPENDIX 19 - WAIT TIMES DATABASES

	Name of Database	Custodian of Database	Data Access
NL	In development Treatment Database (has chemo and RT wait times)	Eastern Health Cancer Care Program	Internal access
NS	Patient Access Registry	Nova Scotia Department of Health	Not requested
PE	ARIA Database	PEI Cancer Treatment Centre	Internal access
NB	Systemic Therapy Wait Times Database	New Brunswick Cancer Network	Internal access
ON	Oncology Wait Times Database	Cancer Care Ontario	
QU	Systeme d'information sur le mechanisme d'acces aux service medicaux specializes (SIMMASS)	Does not contain personal info., info. available in aggregate form	Research Ethics Board approval and Research Resources Impact Committee approval
MB	RT Wait	Cancer Care Manitoba	Internal. Linked within the cancer agency
SK	N/A	N/A	
AB	Not specifically , but within Cancer Care use ARIA for generating wait times	N/A	
BC	Wait times	BC Ministry of Health	No access. Currently under discussion

APPENDIX 20 - LIST OF ACCESS POLICIES/LEGISLATION REVIEWED

British Columbia

Alberta

Alberta Cancer Registry Use of Data, Alberta Cancer Board Policy, 6.A.4.
Alberta Cancer Registry Disclosure of Data, Alberta Cancer Board Policy, 6.A.5.

Saskatchewan

Vital Statistics Act, 2009
Cancer Agency Act, 2009

Manitoba

Public Health Act
Public Health Act Regulation 37/2009
Health Information Privacy Committee

Ontario

Request data from CCO
CD-Link

Quebec

New Brunswick

Nova Scotia

Prince Edward Island

Vital Statistics Act

Newfoundland

APPENDIX 21 - KEY INFORMANTS

Organization	Name	Title/Position
BC Cancer Agency	David Levy, MD	President and Chief Executive Officer
	David Gavin	Director, Data Integration, Population and Preventive Oncology
	Sharon Tamaro	Scientific Director, ,BC Cancer Research Registry
Alberta Health Services	Caroll Russell	Director, Alberta Cancer Registry
	Marcy Winget, PhD	Leader, Research and Evaluation, Community Oncology
Saskatchewan Cancer Agency	Jon Tonita, PhD	Vice President, Population Health
	Riaz Alvi, MSc	Provincial Leader, Epidemiology
CancerCare Manitoba	Donna Turner, PhD	Provincial Director, Population Oncology & Epidemiologist
Cancer Care Ontario	Craig Earle, MD	Program Leader, Health Services Research (CCO + Ontario Institute for Cancer Research)
	Eric Holowaty, MD	Senior Consultant, Population Studies and Surveillance
Direction de la lutte contre le cancer	Louise Paquet, MSc	Agent de recherche et de planification
Prince Edward Island	Kim Vriends	Manager, PEI Cancer Registry
Cancer Care Nova Scotia	Gordon Walsh, MSc	Epidemiologist
Eastern Health	Sharon Smith	Director, Cancer Care Program