Accessing Health Care Utilization Databases for Health Research: A Canadian Longitudinal Study on Aging Feasibility Study*

Parminder S. Raina,[1,2] Susan A. Kirkland,[3,4] Christina Wolfson,[5,6] Karen Szala-Meneok,[7] Lauren E. Griffith,[1,2] Homa Keshavarz,[1,2] Jennifer Uniat,[5] Linda Furlini,[8] Camille L. Angus,[3] Geoff Strople,[3] and Amélie Pelletier[5]

RÉSUMÉ

Une des clés au succès de l'Étude longitudinale canadienne sur le vieillissement (ÉLCV) sera de tirer profit des sources de données secondaires, en particulier données relatives à l'utilisation des soins de santé (USS). Pour examiner les aspects pratiques, méthodologiques et éthiques d'accéder à des données sur l'USS, des entrevues qualitatives individuelles ont été réalisés auprès de 53 administrateurs de données et commissaires/ombudsman à la protection de la vie privée à travers le Canada. Les participants de l'étude ont indiqué que d'obtenir la permission d'accéder à des données sur l'USS est généralement possible; cependant, ils ont noté que ce processus sera complexe et long, exigeant des travaux préparatoires considérables et méticuleux afin de s'assurer que la documentation soit appropriée et que le tout soit conforme aux variations juridiques ainsi qu'aux lignes, législatives et politiques.

ABSTRACT

One of the keys to the success of the Canadian Longitudinal Study on Aging (CLSA) will be the leveraging of secondary data sources, particularly health care utilization (HCU) data. To examine the practical, methodological, and ethical aspects of accessing HCU data, one-on-one qualitative interviews were conducted with 53 data stewards and privacy commissioners/ombudsmen from across Canada. Study participants indicated that obtaining permission to access HCU data is generally possible; however, they noted that this will be a complex and lengthy process requiring considerable and meticulous preparatory work to ensure proper documentation and compliance with jurisdictional variations along legislative and policy lines.

1 McMaster Evidence-based Practice Center, McMaster University

2 Department of Clinical Epidemiology & Biostatistics, Faculty of Health Sciences, McMaster Universiy

3 Department of Community Health & Epidemiology, Dalhousie University

4 Department of Medicine, Dalhousie University

5 Division of Clinical Epidemiology, McGill University Health Centre

6 Department of Epidemiology & Biostatistics and Occupational Health, and Department of Medicine, McGill University

7 School of Rehabilitation Science, McMaster University

8 Research Ethics Office, McGill University Health Centre, Royal Victoria Hospital

* Funding for the Canadian Longitudinal Study on Aging was provided by the Canadian Institutes of Health Research (CIHR), Le Fonds de la recherche en santé du Québec (FRSQ) – Réseau québécois de recherche sur le vieillissement.
Parminder Raina is the recipient of a Canadian Institutes of Health Research Investigator award, an Ontario Premier's Research Excellence award, and holds a Labarge Chair in Research and Knowledge Application for Optimal Aging at McMaster University.

Manuscript received: / manuscrit reçu : 25/08/08

Manuscript accepted: / manuscrit accepté : 13/04/09

Mots clés : ELCV, politique legislative, sources de donnees secondaires

Keywords: CLSA, administrative data, database linkage, health care utilization, privacy

Correspondence and requests for offprints should be sent to: / La correspondance et les demandes de tirés-à-part doivent être adressées à :

Parminder S. Raina, PhD
Professor/Director, McMaster University, Evidence-based Practice Center
1280 Main St. W. DTC Room 310
Hamilton, Ontario, L8S 4L8
praina@mcmaster.ca

Introduction and Background

The Canadian Longitudinal Study on Aging (CLSA) is a large, national, long-term study on adult development and aging. Through its large sample size and longitudinal nature (a minimum 20-year study that will follow 50,000 men and women from across Canada), this study will provide unprecedented research opportunities. In any observational study, the ability to generate, investigate, and test hypotheses is entirely dependent on the nature and quality of the data available. While a major component of the study will be active data collection from study participants, the use of secondary data sources, particularly health care utilization databases, will be an important component of the CLSA.

Health care utilization (HCU) databases contain a potentially rich source of data for health researchers; provincial/territorial health insurance registration data, physician claims data, hospital discharge abstracts, and prescription drug claims have all been successfully used in the past. Accessing HCU data, however, can be a complex, time-consuming, and costly process because serving as a resource for health research is not the primary purpose of administrative databases. The process of acquiring HCU data for a national study is complicated by differing regulations and requirements across Canada's federal, provincial, and territorial jurisdictions.

Other studies (1–3) have acquired HCU data within and across Canadian jurisdictions, but a standard and systematic approach for accessing and utilizing such databases in all jurisdictions does not currently exist. Roos et al. (1) describe the linkage of several administrative databases in Manitoba, Yip et al. (2) linked data from the Canadian Study of Health and Aging to provincial administrative health care databases in Nova Scotia, and Raina et al. (3) linked survey results to health care utilization data in Ontario. To date, no Canadian studies at the national level have linked data across all provinces in an integrated and standardized way. Research in accessing Canadian HCU data suggests that a number of areas require further work in order to facilitate more efficient and cost-effective data access (3–6). Privacy legislation has been undergoing intensive evaluation, and new legislation has either been enacted or is under review in many jurisdictions across Canada. The variation in privacy and confidentiality legislation across provinces and territories poses significant challenges in creating standardized methods for data access, linkage, and storage. The objective of this study was to examine the practical, methodological, and ethical aspects of accessing HCU databases across all Canadian jurisdictions to create a nationally integrated linked data set.

Methods

We collected comparative information on the type and completeness of (and the requirements for accessing) hospitalization, physician billing, prescription drug plan, and health insurance registry databases across Canada. Among the parameters of interest we included were these six: (a) data format, (b) ownership, (c) security, (d) privacy and confidentiality; (d) permission to access; and (e) length of time and cost to access.

Study Design

We conducted a series of one-on-one qualitative interviews with data stewards and privacy commissioners (ombudsmen) from across Canada. We collected data by conducting semi-structured telephone interviews to identify the facilitators and barriers to accessing HCU databases from across the country. The study received ethics approval from McMaster, McGill, and Dalhousie university research ethics boards.

Participants

We generated comprehensive lists of provincial and territorial data stewards (individuals responsible for the definition, management, and access authorization for the HCU database) and federal, provincial, and territorial privacy commissioners (individuals responsible for the administration of privacy legislation), using published articles and books, directories, reports, the Internet, and informal networks. Because of variation in how HCU databases are organized among the jurisdictions, we interviewed between one and three data stewards from each of the 13 provincial and territorial jurisdictions. As well, one federal data steward from the Canadian Institute for Health Information (CIHI) was interviewed. One federal and 13 provincial privacy commissioners were also invited to participate in the study.

Interviews

The interviews were designed to last 45 to 90 minutes. We asked both data stewards and privacy commissioners a series of open- and close-ended questions concerning possible barriers and facilitators to accessing HCU data, including questions about access, ownership, confidentiality and security, transparency, and accountability. Data stewards were also asked more detailed questions relating to the data access application process, privacy and data security, data quality, and the length of time and cost required to access these data. Interviews were audio recorded, transcribed, verified, and returned to participants for checking.

Interviews with English-speaking participants were conducted by the project coordinator who was an

https://doi.org/10.1017/S0714980809990079 Published online by Cambridge University Press

experienced interviewer with training in qualitative methods and health privacy research. Interviews with French-speaking participants were conducted by a bilingual qualitative researcher from Quebec experienced in the areas of privacy and health research. To assure consistency, the interviewer of the French participants was trained by the project coordinator. Ongoing consultation occurred throughout the data collection and analysis phases.

Analysis

To focus, simplify, and abstract the raw data, we placed resulting transcripts into a data reduction table that organized open- and close-ended responses. Data were read and re-read to identify emerging themes. These emerging themes plus the study's overarching research questions, specific issues covered in the interview guide, and interviewees' recommendations provided the analytic categories.

Results

In total, we recruited and interviewed 53 data stewards and privacy commissioners during the summer and autumn of 2005. Data stewards from all federal, provincial, and territorial jurisdictions were interviewed. Only one privacy commissioner from the 14 jurisdictions declined as a result of severe time constraints.

The specific HCU databases that were the focus of this study were hospitalization, physician billing, and prescription. Provincial hospitalization databases generally contain clinical, demographic, and administrative data for each hospital discharge (inpatient acute, chronic, and rehabilitation) or day surgery. For all provinces except Quebec and the non-Winnipeg region of Manitoba, hospitalization records are abstracted to the Discharge Abstract Database (DAD) administered by the CIHI. Thus there is some consistency in the way hospitalization data are collected and reported among the provinces. Billing data for emergency and non-hospital physician care are housed in provincial physician billing databases. Each province also administers its own prescription drug plan database. The population eligible for publicly funded drug plans, however, differs by province (7).

Data stewards and privacy commissioners indicated that obtaining permission to access data from these HCU databases across Canada's 14 federal, provincial, and territorial jurisdictions is generally possible. However, they noted that accessing these data will be a complex and lengthy process requiring considerable and meticulous preparatory work to ensure proper documentation and compliance with jurisdictional legislative and policy requirements. The process for accessing HCU data based on our interviews with data stewards and privacy commissioners is outlined in Figure 1. Essentially, obtaining study participants' consent, research ethics board approval, and privacy impact assessments (a process to determine the impact of a program or service on individual privacy) would need to be completed prior to the formal HCU data requests.

After the data requests are approved, it is expected that the CLSA investigators will provide the data stewards with unique identifying information for each of the 50,000 CLSA participants who agree to have their HCU data accessed, and the provincial data stewards will perform the linkages. Although the general steps are the same, some of the specific requirements to access HCU data differ by province (Table 1). For example, New Brunswick and Newfoundland and Labrador require the Minister of Health to approve the data request, and British Columbia, Manitoba, and Prince Edward Island always require privacy impact assessments (PIA), while in other jurisdictions they are only required after review or not at all.

The anticipated cost of the data linkages differs by province depending on the amount and type of data requested, but most jurisdictions operate on a cost-recovery basis. The estimated time for access ranges from 2 weeks to 6 months. All data stewards agreed, however, that the amount of time needed for subsequent linkages to the same cohort of people would likely be greatly reduced.

The following sections highlight issues raised by the data stewards and privacy commissioners that pertain

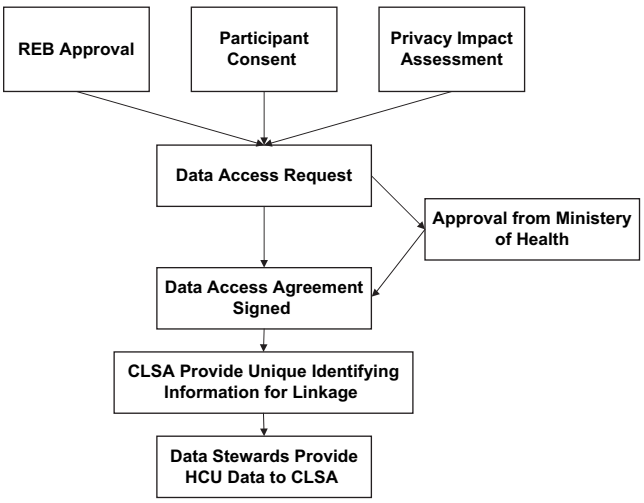

Figure 1: Steps Required to Access Health Care Utilization Data

https://doi.org/10.1017/S0714980809990079 Published online by Cambridge University Press

Table 1: Requirements to accessing health care utilization databases by province and federally

	Provinces and Territories												
	AB	**BC**	**MB**	**NB**	**NL**	**NS**	**ON**	**PE**	**QC**	**SK**	**NT**	**NU**	**YT**
REB Approval	DU	PRO, OTH[b]	PEC	PRO[a]	PRO,[a] DU	DU	DU	DU	PRO	DU	OTH[c]	OTH[d]	NA
PIA Required	PR	R	R	NR	NR	PR	NR	R	NR	NR	NR	NR	NR
Approval by Minister of Health	REC	NR	NR	R	R	NR	NR	NR	NR	NR	NR	NR	NR
PHN Availability	C,D	C,D	C,D	C,D	C,D	C,D	C,D	C,D	C,D	C,D	C,D	C,D	C

AB=Alberta; BC=British Columbia; MB=Manitoba; NB=New Brunswick; NL=Newfoundland and Labrador; NS=Nova Scotia; ON=Ontario; PE=Prince Edward Island; QC=Québec; SK=Saskatchewan; NT=Northwest Territories; NU=Nunavut; YT=Yukon; PIA=Privacy impact assessment; PHN=Personal health number; REB=Research Ethics Board; PRO=Provincial EB; DU=Designated University REB in the jurisdiction; PEC=Privacy or Ethics Committee; OTH=Other; R=Required; PR=Possibly Required (after review); REC=Recommended; NR=Not required; C=PHN may be collected from participants; D=PHN may be disclosed by Ministries of Health

[a] Possibly in future

[b] Pharmanet Stewardship Committee

[c] Possibly the Aurora Research Institute

[d] Dept. of Health and legal counsel and Nunavut Research Institute

to the linkage to HCU databases as part of a long-term longitudinal study such as the CLSA.

Privacy and Confidentiality

Data stewards and privacy commissioners emphasized that careful attention to privacy issues will be required in order to access HCU data. For example, participants from smaller jurisdictions could potentially be identified because of unusual diseases, unique health conditions, or specific geographic location. When using HCU data for research purposes, the need for a PIA differs by province (Table 1). Even when PIAs are not required by a province, they are viewed as a good practice. It was recommended that, together with jurisdiction-specific PIAs, an overarching PIA study should be considered. Such a PIA study would provide a clearer overall picture of the impact of the proposed research on privacy issues, contribute to the design of the consent process and documents, and demonstrate ongoing commitment to transparency and accountability.

In most jurisdictions a personal health number (PHN) is used to access HCU data. Provinces differ in regard to the collection of personal health numbers from study participants or its disclosure by respective ministries of health (Table 1). Most jurisdictions do not restrict researchers from collecting the numbers; however, interviewees indicated that collection and disclosure of PHNs would have to be addressed in the consent process.

Consent

For studies with a long period of follow-up and broad scope such as the CLSA, interviewees recommended that consent be obtained from study participants to access their HCU data, even if legislation does not currently mandate it. The overall view of privacy commissioners and data stewards was that there should be explicit opt-in consent for study participation to ensure protection of the participant and to satisfy privacy concerns. In addition, the interviewees indicated that investigators should establish a number of policies that deal with the potential withdrawal, loss of cognitive capacity, and death of a study participant. Furthermore, the consent process should ensure participants that their participation or withdrawal from the study is in no way tied to their receipt of health care services.

Some data stewards and privacy commissioners brought up the likely need for ongoing consent for studies, such as the CLSA, with a very long time horizon. While ongoing consent does not appear to be legislated or a hard and fast policy, it repeatedly surfaced in discussions and is essentially expected in many of the provinces. Consent documents would need to be reviewed by privacy commissioners and data stewards to ensure that they comply with jurisdictional policies and legislation and should contain a section that addresses the possibility that participants might move to another Canadian jurisdiction during the time span of the CLSA. If a study participant moves from one jurisdiction to another over the life of the study, proof of

https://doi.org/10.1017/S0714980809990079 Published online by Cambridge University Press

consent will need to be registered with the new jurisdiction of residence before data could be released.

Finally, interviewees mentioned that, given advances in electronic health records (EHR), investigators may want to ask participants for consent to access their EHR even if not yet implemented. This could potentially save investigators from having to go through a new consent process when EHRs become the standard operating procedure in most physician offices.

Accessing HCU Data for First Nations and Inuit People

First Nations and the Inuit represent a significant portion of the population in Canada's three territories and northern regions of most provinces. Data stewards and privacy commissioners noted that accessing HCU data associated with Aboriginal Peoples will require special considerations as there are cultural sensitivities, logistical challenges, and legal requirements that will need to be addressed.

Interviewees noted that in their experiences, Aboriginal Peoples' involvement with scientists have not always been positive, and many are very cautious and sceptical about how they will benefit and how they will be portrayed in the research findings.

Because Aboriginal Peoples constitute an easily identifiable population, many have been reluctant in the past to participate in health research studies for fear of being stigmatized. Data ownership (especially of biosamples and genetic material) could be an extremely sensitive issue even if individual consent were obtained. Interviewees recommended that it is important to invite Aboriginal People into the early stages of the study design, and to inform them of the benefits that would be accrued to this population.

Together with dealing with cultural sensitivities, interviewees noted that language barriers will need to be addressed. Because some older Aboriginal Peoples may not be completely fluent in either of Canada's official languages, consent and data collection may need to be conducted in their first language (16 languages in the Northwest Territories and 2 in Nunavut). Interviewees noted that many older Aboriginal Peoples who speak an Aboriginal language do not necessarily read in the same language. Furthermore, some languages may not have vocabulary for certain terminology related to the study.

Other Data Issues

Cross-Jurisdictional HCU Data Issues

Due to the reciprocity of the Canadian public health care system, the home province or territory reimburses the costs when a resident receives health care in another jurisdiction. Some jurisdictions reported to the investigators, however, that there is variability in the completeness of information returned to them by the province or territory that provided the care. This could compromise the quality of the data or the receipt of data in a timely fashion. The interviewees suggested that CLSA investigators could potentially access cross-jurisdictional health care data directly from the province or territory where the care was provided. In this instance, it is likely that consent to disclose this information would need to be proven to the ministry of health where the care was provided.

In addition to Canadians' potentially receiving health care in many different jurisdictions in Canada, some also may receive care in other countries. For example, many Canadians spend part of the year in the United States. In addition, some First Nations people who travel across the United States/Canada border may be accessing health care systems in both countries. In relation to the United States, interviewees suggested that the United States Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule and other aspects of the legislation may influence access to this information and thus should be investigated.

Lack of HCU Data Standardization

It was noted by data stewards that the lack of standardization across jurisdictions with regard to HCU data collection, maintenance, sharing, comparability (types of variables and method of coding), and completeness would be an issue for studies involving multiple jurisdictions. For example, prescription drug data is unavailable in Newfoundland and Labrador. Hospitalization data are sent directly to the CIHI from participating hospitals in every province and territory except Quebec. Quebec hospitalization data are not classified by the same parameters as other hospitalization data that are processed through CIHI. Although harmonization efforts are currently under way with the Canada Health Infoway(8), a not-for-profit organization collaborating with the provinces and territories, health care providers and technology solution providers to accelerate the use of electronic health records (EHRs) in Canada, there is still a great deal of work to be done in this regard, and the data stewards suggested it might take as long as a decade to accomplish.

Similarly, although the International Classification of Disease, Canadian Specific Modification (ICD-10CA) is generally used in the HCU databases, there is a lack of standardization inter-provincially. In addition, there could be some inconsistency in coding between one hospital and another within a jurisdiction. Generally, data stewards reported that because most hospitalization data are abstracted to CIHI, they believe that data

https://doi.org/10.1017/S0714980809990079 Published online by Cambridge University Press

are generally consistent at least within a jurisdiction. An issue involving coding accuracy by individual physicians (or billing clerks) was noted by various data stewards, who pointed out variability among physicians' use of the codes.

Data Validity

In some jurisdictions, various data stewards administer the different HCU databases. Ministry branches that conduct validity and reliability checks can also vary from database to database within a jurisdiction. Most jurisdictions have electronic billing, but in some locations such as in the territories, some manual systems were still in place at the time of this study. For physician billing and prescription drug plan databases, all jurisdictions run a variety of validation tests on a routine basis.

With regard to health insurance registration data, the data stewards recommended that data scrubbing might be required to ensure matching of the correct registrant with the correct personal health information number. Generally, all jurisdictions reported that data were rigorously checked, rechecked, screened, and underwent numerous standard audit procedures. Interviewees suggested that every effort be made to ensure the accuracy of each personal identifier and corresponding PHN to facilitate HCU data access.

Updating HCU Data

Data stewards reported that corrections can be made to HCU data six months and even longer after it has been reported. It would therefore be important, at the time data access agreements are being negotiated with the data stewards, to ascertain when the data would be considered complete and final.

Changes in the practice will also occur over time. Stakeholders commented that the categories of health care providers are very likely to evolve over the next 20 years, and that this would impact longitudinal studies like the CLSA. Traditionally, general practitioners have provided primary care, but now nurses are being trained to provide some of that care. It is likely that the primary care model will be extended to other health care providers in the future, which would result in more categories of health care providers added to HCU databases.

Data Security

Interviewees noted that research involving HCU data should employ industry-standard administrative, physical, and electronic procedures relating to data security. In addition, security exemplars should be considered to ensure that security breaches either internally or externally be avoided. These standards should focus on the physical and electronic protection of personal health information as well as secure transmission procedures when data are moved from the data steward/custodian to authorized/designated CLSA researchers.

Data Retention

Interviewees stated that there are no clear guidelines or policies regarding time limits on data retention or destruction. There was significant variability in how jurisdictions dealt with this issue, and to a large extent, jurisdictions were following previous practices applied to other studies. The data stewards explained that data access agreements would need to address three key topics. First, the data access agreements would have to explain plans for concluding the study and destroying the data. Second, the agreements would need to explain how, if the study lives on, what form it would take, and who it would be that would ensure the safeguarding of the study participants' privacy and confidentiality. Third, the agreements would have to explain that the data would not be used for purposes other than those initially agreed upon.

Data Usage beyond the CLSA Investigators

Among the topics raised by data stewards and privacy commissioners was the use of study data by those other than the principal investigators (e.g., by study collaborators) and for purposes not necessarily detailed at the start of the study. Interviewees commented that when granting HCU data access, they require to know who beyond the principal investigators will have access to the data. Given the length of a study like the CLSA, protocols and policies will need to be developed to address these concerns, including such topics as investigator attrition and new investigator recruitment over the course of the study. A recurrent concern raised by data stewards and privacy commissioners related to how the long-term nature of studies like the CLSA complicates future use of the data. For the most part, permission to access HCU data requires investigators to provide highly specific details on how the data will be used. It is very possible that, in the future, investigators will wish to use data in a manner that was not initially contemplated and documented—for example, the linking of HCU data to other databases not considered at the launch of the study or to databases that do not yet exist.

Among the recommendations data stewards and privacy commissioners provided regarding all these concerns was the necessity for carefully designing the consent process and the likely need to revisit data usage permission throughout the study. Furthermore, the data stewards and privacy commissioners recommended that establishment of a data access committee be considered and data access guidelines be prepared.

The structure and operation of the study's internal data access committee will need to satisfy the various data security expectations of the jurisdictions involved.

Facilitating the HCU Data Access Process

It was generally felt by interviewees that the most efficient approach to request database access would be to request access to all relevant HCU databases at the same time. In the case of the CLSA, this would involve hospitalization, physician billing, prescription drug plan, and health insurance registration data. A number of stakeholders strongly recommended that CLSA investigators initially consult with the offices of the privacy commissioners and assistant ministers of health to inform them that they intended to submit requests to access HCU data. It was explained that this could contribute to greater support for the study to ensure that its data requests were processed in a timely and efficient manner and that any questions the ministry or the public might have could be addressed.

In some jurisdictions, access to hospitalization, physician billing, prescription drug, and health insurance registration databases are coordinated by one ministry branch or unit; this would facilitate the initial correspondence, data access agreements, and ethics and privacy impact assessments where applicable. This scenario tends to apply to the larger jurisdictions where there is a history of greater internal ministry research on HCU data as well as more requests from health services researchers. In smaller jurisdictions, there is generally less centralization of the data access process, and investigators potentially need to deal with several different government units.

Data stewards and privacy commissioners believed that data access agreements would drive the data application process. Because of this, they recommended that these documents be drafted iteratively and in collaboration with ministry staff. Many of the larger jurisdictions have document templates; others request a detailed letter that serves as a data request document. Some jurisdictions have privacy impact assessment documents, and additional ethics approval steps may be required.

Participants advised that it is often difficult to provide definitive estimates concerning the cost to access data or the length of time to receive data. This is particularly true with large studies. In the case of the CLSA, some estimates were provided but with the caveat that they were based only on other studies. With regard to length of time to receive data, estimates ranged from several weeks to 12 months. It was recommended that investigators build in ample lead time to work with responsible departments within various ministries of health to reduce obstacles and keep the lines of communication open. Most jurisdictions operate on a cost recovery basis and would either assign existing ministry programmers and other staff or would hire contract personnel to conduct the data extraction required. Data stewards reported that delays could occur due to staffing issues. One interviewee recommended that in the case of the CLSA, investigators should establish internal ministry champions who could help expedite CLSA's data requests through the system. The interviewees reiterated, from their experiences with other studies, that preparing materials carefully with ministry staff would help reduce obstacles.

Discussion

On the basis of results from this study, it appears that obtaining permission to access information from HCU databases (provincial health insurance registration, physician claims, hospital discharge abstracts, and prescription claims) across Canada's 14 federal, provincial, and territorial jurisdictions is generally possible. However, it was noted and stressed that accessing these data will be a complex and lengthy process. The initial stage in the data accessing process will be the most problematic, lengthy, and costly, but once under way, the process could be streamlined.

Despite the existence of many common policies and practices across the jurisdictions, there is enough variability to pose some important challenges to HCU data access. It will be useful to capitalize on the multiple common policies and procedures that do exist and use them in conjunction with what is recognized as good practice in the conduct of research involving human subjects (i.e., tri-council ethics guidelines) to structure the study's core documents. These core documents will then be tailored to meet each province's needs.

Given the complexity and lengthiness of the HCU data access process, it will be important for investigators to develop strong working relationships with data stewards and managers. Although the data stewards are adept at the process of linking HCU data to other databases, many of the issues related to providing data for a long-term nationwide study have no precedent. Given the scope and longitudinal nature of the CLSA, jurisdictions may need to create unique policies and procedures to accommodate the study. For example, some provinces do not allow HCU data out of their jurisdiction. This has important implications for the CLSA if central data storage (of anonymized data) is anticipated. With regard to data retention and destruction, there is similarly little precedent for a research platform like the CLSA in which long-term data usage is critical. As well, it is anticipated that over time new and novel research questions will be generated that

https://doi.org/10.1017/S0714980809990079 Published online by Cambridge University Press

were not even considered at the beginning of the study. None of these issues have a simple answer, and addressing them will require a collaborative model that includes researchers and data stewards, privacy commissioners, provincial ministries, and other stakeholders to ensure that the research is done in a way that guarantees that participants' rights and privacy are respected.

It is clear that accessing HCU data will be a challenging undertaking. Nevertheless, the results of this study help to clarify the issues that researchers must address in preparing for longitudinal multijurisdictional studies involving HCU data and provide some guidance on how to best navigate the complex process. Understanding these issues is an important first step to developing a harmonized process of HCU data acquisition in federal, provincial, and territorial jurisdictions across Canada.

References

1. Roos, LL, Brownell, M, Lix, L, Roos, NP, Walld, R, MacWilliam, L. From health research to social research: Privacy, methods, approaches. *Soc Sci Med* 2008:117–129.
2. Yip, AM, Kephart, G, Rockwood, K. Linkage of the Canadian Study of Health and Aging to provincial administrative health care databases in Nova Scotia. *Int Psychogeriatr* 2001;*13*(suppl 1):147–158.
3. Raina, P, Torrance-Rynard, V, Wong, M, Woodward, C. Agreement between self-reported and routinely collected health-care utilization data among seniors. *Health Services Res* 2002;*37*:751–774.
4. Kephart, G. *Barriers to accessing and analysing health information in Canada*. Ottawa: Canadian Institute for Health Information, 2002.
5. Black, C, McGrail, KM, Fooks, C, Baranek, P, Maslove, L. *Data, data everywhere: improving access to population health and health services research data in Canada*. Vancouver: Centre for Health Services and Policy Research, 2005.
6. Holbrook, A, Keshavjee, K, Sebaldt, R, Grootendorst, P, Levine, M, Goldsmith, C et al., *Evaluation of data sources to support pharmacosurveillance*. Final report of the Health Policy Research Program, Health Canada. 2005.
7. Demers, V, Melo, M, Jackevicius, C, Cox, J, Kalavrouziotis, D, Rinfret, S, et al. Comparison of provincial prescription drug plans and the impact on patients' annual drug expenditures. *CMAJ* 2008;*178*:405–409.
8. Canada Health Infoway. [cited 2008 Aug 8]. Available from: URL: http://www.infoway-inforoute.ca/en/home/home.aspx

https://doi.org/10.1017/S0714980809990079 Published online by Cambridge University Press