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HUMAN HEALTH, WELL-BEING AND DEVELOPMENT.

Data Access Review Times Study: Report

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Background

A 2011 International Review Panel Report for the Canadian Institutes of Health Information noted the unique population data capacity that exists in Canada, indicating it could place Canada in a strong strategic position internationally for health research. In the same report, the frustration experienced by researchers for (lack of) access to health data was also highlighted. This dichotomy of presence of the data but challenges with access was criticized by the panel: "To have data which can be used to prevent harm and improve services and not to make it available is morally culpable." [1]

There has not been an overview report on the state of access to health administrative data in Canada. This study sought to initiate this, with specific emphasis on who can request access to data, the procedures involved in requesting access, and the timelines from the initiation of the request to the receipt of data.

Access decisions largely hinge on the weighing of potential (public) benefit to potential (individual) harm in the context of governing legislation. Given this, the present study provides a lens on how each province manages or balances these privacy-related considerations when making decisions about research requests for access to data.

Study Objectives

The overall objective of this study was to provide an empirical base for the ongoing conversations in Canada about the problems with data access. The sentiment that there are problems is widespread, but details around where those problems occur, for whom, and what the specific drivers might be are lacking. The more specific objectives of the study were to describe:

- where access to health administrative data takes place in each of Canada's 13 jurisdictions
- the processes in place to support such access
- restrictions on access
- typical timelines for access
- factors affecting timelines for access.

Study overview

Ministries of health were contacted in each of the 10 Canadian provinces and three territories with the intent of identifying access routes to health administrative data. In some cases, those Ministries were the relevant organization, but in other cases there were other or additional bodies or centres involved. All relevant agencies were invited to participate in the survey. The focus was on provincial bodies, and

[1] http://www.cihr-irsc.gc.ca/e/43993.html

for this reason neither Statistics Canada nor the Canadian Institutes for Health Information have been included.

Survey respondents included:

- Population Data BC (PopData)
- Alberta Health Services (AHS)
- Alberta Health (AH)
- Saskatchewan Ministry of Health (SK MOH)
- Manitoba Health (MB Health)
- Manitoba Centre for Health Policy (MCHP)
- Ontario Ministry of Health and Long Term Care (ON MOHLTC)
- Institute for Clinical and Evaluative Sciences, ON (ICES)
- Dalhousie Population Health Research Unit (PHRU)

Note Saskatchewan Ministry of Health only completed part of the survey, regarding processes. Because of variability in types of data requests and multiple points of access to data, this organization was not able to report on timelines.

Sites interviewed but not included in this report because they were not vetted at time of writing:

- Saskatchewan Health Quality Council
- Québec Institut de recherche et d'informations socio-économiques
- Newfoundland and Labrador Centre for Health Information

The following were not interviewed, with reasons provided:

- Yukon: Does not provide research access to health data other than cancer data.
- Northwest Territories and Nunavut: Records are primarily paper based, and not routinely used.
- New Brunswick and Prince Edward Island: Requests are infrequent and there are no standard processes in place.

Organizations were given the option of sending in written responses to the survey, or to schedule a phone interview. In all cases, phone interviews took place. Most interviews took place with a single representative of the organization in the area responsible of data access, although in a few cases there was more than one person on the phone call. The responses were documented within the survey instrument, sent back to the respondents for accuracy and additions.

The consent form provided indicated that responses will be summarized and shared with respondents, that they will be used for public discussion purposes, and may be developed into a paper for publication. Names of those interviewed will not be reported. The University of British Columbia Behavioural

Research Ethics Board provided review and approval for the study. The survey instrument used is included as Appendix A.

Results

There are a few important notes to make at the outset.

Research data access is a complex field which does not lend itself to clear, 'cookie cutter' requests. Requests can be complicated, labour intensive, and challenge those involved to adapt processes. Each jurisdiction struggles with trying to find simplicity in the context of this inherent complexity. In light of this, there was admitted discomfort on the part of many of the respondents in terms of reporting on the numbers. It is hard to separate the numbers from the context. This needs to be acknowledged in advance of reviewing any of the results.

Following this, direct comparisons in access times among centres reported in this study need to be put in the context of the significant variation in the types of centres, types of access available, as well as when each centre starts counting time. It may be easy to lose sight of this when numbers are reported in a table. That said, there are still worthwhile patterns to look at and to learn from, which is why we have chosen to represent some information in detail.

All reporting done here is by the organizations offering data. No efforts have been made to vet the information provided i.e. by the researcher community.

Brief orientation of the centres interviewed

Population Data BC: A university based organization dedicated to supporting research access to linked administrative data, including data external to health. The Ministry of Health no longer mediates research access to data; requests are directed to Population Data BC. The organization employs staff who work with researchers to develop the application, coordinate reviews, and then extract the data.

Alberta Health Services (AHS): There is a new group set within AHS's Data Integration and Management Reporting department with dedicated, specialized "Data Liaisons" that work directly with researchers to support their request development and execute extracts. Many projects fall under 'quality improvement' and thus are able to proceed with less external review than projects deemed as 'research'. Data linkage typically occurs only within the health domain.

Alberta Health (AH): A unit within AH handles research requests. Health Information Legislation enables research access however it limits the ability to link outside of the health domain. This group only links within health and to Vital Statistics. The analysts in the unit have other commitments, including responding to non-research-related requests for access to data.

Saskatchewan Ministry of Health: The Epidemiology and Research Unit within the Population Health Branch handles only requests needing data from more than one data source (which might be two different health sources within the ministry, or a health data set plus an external data set.) Other research requests for data from a single data source are handled by other branches or agencies.

Manitoba Centre for Health Policy: Based at the University of Manitoba, this repository-based resource holds linkable data from a wide variety of different sources, not just health. The Centre has dedicated staff to support access to and analysis of the data. It is possible for researchers not affiliated with the MCHP to apply for and access the data at MCHP.

Manitoba Health: Access requests for health-only data can be directed to the Health Information Management branch of Manitoba Health.

ICES: A not-for-profit organization that has designated status in the Ontario health privacy legislation. To access the data directly one must be an ICES-affiliated faculty and have completed specific privacy-related training. Most analysis is done through dedicated staff analysts. ICES fields a number of rapid response requests for analysis by the Ontario government. There are about 150 ICES scientists throughout Ontario. Access to ICES individual level, de-identified data is on-site or through dedicated VPN lines supported through 4 centres (ICES Ottawa, ICES UofT and ICES Western – currently McMaster and a line in the Ontario North is being discussed).

Ontario Ministry of Health and Long Term Care: Part of the Health System Information Management and Investment Division, the Information Management Strategy and Policy Branch, this group supports access to individual-level Ministry data only (identifiable or non-identifiable). Another group supports aggregate data access requests.

Population Health Research Unit: This is based at Dalhousie University, and provides access to linked data within the health domain. Most requests are provided with aggregate data.

Data access: type, volume and backlog

Access is provided in most cases through a government entity. Where there is a non-government entity its focus is solely research, whether performing or supporting or both.

While all entities support access to individual-level data (which may have some fields aggregated, such as date of birth into month of birth), some additionally support provision of aggregate data. This often went together with offerings of analytic support. Where analytic services were offered, the proportion of requests being individual-level data requests was generally much lower, save in the case of Alberta Health Services.

Backlogs were reported as negligible in all but two locations. These were both government units which had priorities that included both research and non-research, with research typically being of lower priority when staffing capacity issues become an issue.

	Entity type	**Is aggregate level data provided?**	**Request for individual level data as a % of all requests**	**Are analysis services offered?**	**Typical volume of requests / year**	**Backlog of requests**
PopData	University	No	100%	No	15-25	Negligible
AH	Gov't	Yes	80%	No	65-100	45
AHS	Gov't	Yes	80%	Yes	60++	No
SK MOH	Gov't	Yes		No		
MCHP	University	Yes	20%	Yes	40-50	Negligible
MB Health	Gov't	Rare	95%	Rare	40-70	Negligible
ICES	Non profit	Yes	100%	Yes	230	External data requiring data sharing agreements
ON MOHLTC	Gov't	Not this group	100%	No	30-40	15-20
PHRU	University	Yes	25%	Yes	70-90	Negligible

Approvals and access

There are typically two core components to reviews: research ethics board approval, and data custodian approval. Some centres include additionally a specific privacy review.

Research ethics board: It is standard across all centres that research requests require research ethics board approval. The only exceptions were a) when projects are considered quality improvement through AHS, and b) projects using only Ministry of Health data in Saskatchewan (projects that link MOH data with data from outside the MOH require ethics committee approval.)

Data custodian: The approach to data custodian reviews varied quite considerably. In some cases, there was a clear requirement for a formal approval by designated custodians for each of the data sets involved in the request. In others, in particular where access was embedded in government, approvals were implicit through the provision of data and signing of research agreements. In two cases there were committees set up to handle the custodian / stewardship function. In Saskatchewan, this is a committee internal to the Ministry of Health called the Data Access Review Committee. This Committee checks that the project is feasible and confidentiality is maintained. In Nova Scotia, the Data Access Committee reviews all applications and consists of members from the university's Department of Health Care and Epidemiology as well as the Nova Scotia Department of Health and Wellness.

In all cases where external data was linked with data in-house, specific custodian approvals were necessary.

	Committee review	**Specific individual signoff**	**Not formalized / de facto review through application development process**	**Notes**
PopData		Yes		All originating data stewards approve projects using their data
AH			Yes	
AHS			Yes	
SK MOH	Yes			Internal committee to MOH
MCHP	**		Yes	MCHP has custodianship over health data; Custodian reviews needed for data outside scope of HIPC
MB Health	**		Yes	
ICES			Yes	
ON MOHLTC			Yes	
PHRU	Yes			

** Manitoba has the Health Information Privacy Committee (HIPC) review, which while not technically the custodian, performs the primary review for research access in Manitoba. More on this in the next section.

Privacy: While addressing privacy concerns is clearly a core part of custodian reviews, three centres have additional review processes that are specifically referenced as a privacy review. In many respects these could be considered a component of the custodian review but because they are spoken of separately are represented independently. These were:

- In Manitoba, all research requests (both from MCHP and MB Health) must go through a Health Information and Privacy Committee. This committee is responsible for approving health research projects that use personal health information held by a government department or agency, weighing whether the importance of the research outweighs the (potential) intrusion into privacy. There are 8-12 members with broad representation from the public, health authorities, physicians, nurses, medical records and pharmacy.
- ICES has developed a Privacy Impact Assessment that is used for all projects. Each PIA is reviewed by their Privacy Officer. There is also a Request for Data form for external data linked with ICES data. The PIA and the RFD together outline the data requested and research questions; in other jurisdictions this would be considered a data access request form.
- ON MOHLTC performs what they term a privacy review / risk assessment which may involve a single member of the team, or two members for more complex requests. The legal

services branch gets involved in drawing up the Research Agreement, which is tailored to each project.

Who can access and how

Access to health administrative data in half the centres is restricted to university-affiliated researchers only. In the other half, non-University-affiliated researchers and analysts are able to apply for the data through the same mechanism as university-affiliated researchers. A non-University-affiliated researcher may work for example in a hospital, a health authority, government or industry.

Other than Population Data BC, the designated research centres require physical presence to be able to access / analyse the individual-level research extracts.

For the centres that supported delivery of research extracts (generally government entities), the delivery was typically done on encrypted CD. In many jurisdictions, this delivery was allowed outside of provincial boundaries. In some cases, delivery was permitted outside of Canada. Details are provided in the table below.

	Non-"researcher"?	**Access location**	**Delivery mechanism**	**Notes**
PopData	No	Anywhere in Canada	Remote access to server	Delivery by sftp supported rarely
AH	No	Anywhere in world	Encrypted CD / DVD	
AHS	Yes	Anywhere in world	Encrypted CD	
SK MOH	Yes	Anywhere in world	Encrypted CD	If small numbers do not permit release of data, analyses may be done at MOH
MCHP	Yes	At MCHP	Data not delivered	Access only for "research"; needs to have U of M HREB, requiring significant local academic participation in study.
MB Health	Yes	Anywhere in MB	Encrypted CD	
ICES	No	At ICES	Data not delivered	There are 5 access points in the province for ICES scientists
ON MOHLTC	Yes	Anywhere in Canada	Encrypted CD	Only aggregate data may be delivered outside of Canada.
PHRU	Yes	At PHRU	Data not delivered	Industry access allowed only for research in collaboration with

				researchers from Dalhousie/Capital Health/IWK and it requires approval of MOH

Timelines

As referenced at the outset, trying to pin down numbers on timelines was challenging for most centres, in part because of project variability but also because there is no standard place to start the clock. Through discussion and review, we believe the timelines below reflect the time between when researchers actively pursue an application for data to when they receive data.

Centres can be clustered into "faster" (up to 4 months), and "slower" (5 months or more.) There is more variability among the "slower" centres, where some projects proceed quite quickly while others take longer or become "stuck" for a variety of reasons.

In seeking to categorize common driver of timelines, the following categories were used in the context of the survey:

- Data custodian review: where the decision making by the data custodian was something that added in a substantive manner to timelines. Population Data BC was the only centre that identified this as a contributor.
- Researcher responsiveness: although researchers are making the request, a number of centres noted that some of the timelines should be attributed to researchers not responding in a timely fashion to questions or clarification requests. This was more present for the 'slower' centres.
- Researcher experience: while not on the survey instrument itself, 3 centres identified this as a factor in timelines. New researchers often require more labour input on the part of the centre to support application development. Experienced researchers are able to more clearly stiplulate their request, and with better familiarity with the data, correctly identify the data required.
- Complexity of the research project: this was supported by all the centres – the more complex the project (e.g. complex cohort, sensitive populations, multiple data sources being linked) the more work involved not just in the data preparation, but also in getting the request clear and consistent.
- Privacy uncertainty: while not very specific, this category brought forth stories regarding interpretation of legislation, and how this affected the types of decisions made or the speed at which they might be made. While privacy legislation explicitly supports research, privacy best practices such as ensuring minimum data and minimizing identifiability influenced the allowed scope of the request and in turn the back and forth with the research team. Where there is scrutiny around what data is allowed to be released, there is no clear standard applied.
- Staff capacity: also not on the original survey as a category, many identified this as a rate limiting step, primarily among groups within government.
- Funding: identified by MCHP, ON MOHLTC and PHRU as affecting timelines. This relates to their ability to start the initiation process prior to grants being awarded, which may not be present in other jurisdictions.

		Drivers of the total timeline						
	Total timeline	**Data custodian review**	**Respon-siveness**	**Exp-erience**	**Com-plexity**	**Privacy uncertainty**	**Staff capacity**	**Funding**
PopData	6-12 mos	X	X	X	X	X	X	
AH	12-18 mos		X		X	X	X	
AHS	> 1 mo				X		X	
SK MOH								
MCHP	4 mos				X	X external		X
MB Health	4-7 mos		X	X	X		X	
ICES	1-2 mos							
ON MOHLTC	3-12 mos	X	X	X	X	X	X	X
PHRU	1-2 mos		X		X	X		X

Summary

Access to health administrative data for research in jurisdictions across Canada is marked by significant variability in areas that affect the research enterprise:

- Timelines for access: from 1 month to 18 months on average
- Who can access: from affiliated researchers only to industry analysts
- Where they can access: from on-site only to delivery internationally
- Approaches to reviews: from individual review to committee review
- Volume of requests received and satisfied: from a dozen to hundreds
- Available data: from health only to cross-sectoral data

Enabling conditions for timely access

The fundamental consideration in assessing access to administrative health data for research purposes is that of privacy – that the benefits of the research outweigh the potential privacy impact, and further that privacy risks are minimized. Across Canada the privacy legislation is substantively similar, allowing for explicit access to administrative health data for research purposes. Each jurisdiction has approached access in their own unique way to address local needs, specific legislation, history and capacity. There are no two centres where the approach to access is the same; in this study we have nine examples of privacy risk management regarding research access to data.

Laid over this, the original question that spurred the survey was whether or not there is a problem with data access in Canada. While this is a highly subjective question, it generally refers to whether data is available within a reasonable timeline. What is 'reasonable' can be debated, but at a minimum we should consider that when one applies for and receives grant funding, the research team can reliably gain access within the time frame of the grant. Few would argue that over six months is reasonable. 2-4 months is a time frame supported by many respondents. Of the nine participants in the survey, there are four centres that would meet this criterion.

What are some of the key features that allow those four centres to address privacy risk in a timely fashion? The following are some practices noted that appear to influence their success. There are many layers of context to each, so these are more points of consideration than conclusions that can be applied directly elsewhere.

1) Clarity on reviews and authorities. Two approaches to this are seen in practice:

- External committee review. These committees in Manitoba and Nova Scotia include membership from key stakeholder organizations, have developed institutional knowledge, meet regularly and are purpose-built to address privacy issues in research access to data. This enables not only a broad perspective but also more decisiveness than seen by single custodian reviews.
- Clarity in legislative interpretation. For ICES, there is legislation providing designated status and for MCHP they are named in the legislation. Together with internal processes, these centres are able to narrow down the scope and handoffs required in reviews. In Alberta's AHS, there is a stated management directive that research access will be supported. This is accompanied by confidence in interpretation of the legislation. This has reduced the privacy uncertainty that frequently brings delays. The two examples are interesting in that clarity may not need legislative change, however it does need decisiveness in interpretation.

2) Dedicated staff to the research enterprise. In all four examples, dedicated staff are in place to support research access to data. AHS, the only in-government 'faster' centre, has designated epidemiologists. MCHP, ICES and PHRU are established primarily as research enterprises, allowing for the organizational and management structures to be built around optimizing researcher needs.
3) Security of data post-approval. In 3 of the 4 'faster' centres the data extract does not leave the physical premises and researchers need to come to a designated site for analysis. In addition to control over proliferation of the data and its protection, it also prevents subsequent linkages, unauthorized analyses, and restricts who is able to use the data. This is another prong in their privacy risk management: the centres maintain control over the data post-release. PopData through their Secure Research Environment is able to addresses this same privacy risk in a de-centralized fashion. These conditions support the custodians concerns and responsibilities when it comes to data protection.

Two additional drivers of timelines that are common across centres are researcher experience with the data and project complexity.

Project complexity may occur for multiple reasons, but frequently it is driven by inclusion of multiple data sources. Given the value of cross-sectoral research and growing interest in population health, this is an area that is likely to grow in importance, but it does present an additional layer of privacy risk considerations. The dedicated research units are the ones that have addressed this challenge - MCHP and PopData, and increasingly ICES and PHRU.

Researcher experience is a challenge for most centres. Examples of interesting efforts here were the availability of a sub-sample dataset in MCHP to support researcher familiarity with the data, and intensive documentation efforts through for example the concept dictionary at MCHP and a metadata initiative being built at PopData. PopData additionally has training courses that employ real administrative data to help build capacity for use of administrative data. There are likely opportunities to collaborate across centres to further support capacity building of new researchers.

Ideas moving forward

Through the course of the interviews, additional thoughts and questions arose that aren't necessarily connected to timelines but are nonetheless interesting and important for research data access in Canada.

Who can access: academic / non-academic: In half the centres, access is open for academic researchers only. The other half allow broader access for research purposes, whether by clinicians or even those working in industry. Assuming that privacy risk considerations are well addressed, broader access could increase the volume and scope of research, shedding more insights into human health and well-being. Understanding what enables this broad access would be of significant interest.

Who can access: affiliate / open: One characteristic in two of the 'faster' centres is that of affiliated researchers only being allowed access. This likely supports the model in those regions of more rapid access given it provides a form of vetting and credentialing of those who access data. However it presents a barrier for non-affiliated researchers. The barrier means that the provincial ministries of health also continue to facilitate research requests. Consideration should be given to that component of risk management and if there are alternate ways to vet or credential researchers in order to support greater access.

Access beyond health: while referenced in the previous section, this warrants a continued discussion. Some health specific legislation, while explicitly supporting research access, has had the effect of limiting access beyond health only. Was this an oversight? Or a reflection of how health research was

characterized a decade ago? For those provinces considering new privacy or health legislation, this should be taken into consideration, because the ability to link across domains is an area of increasing value and importance.

Conclusion

The clear directive from the CIHR review was that more should be done to support data access, and to support the ability for researchers to conduct cross-provincial research. It would be difficult to make the step to cross-provincial research without having more reliable and timely in-province access processes in place. Access processes are largely dictated by privacy risk management, there is potential to learn from each other about ways to manage privacy more efficiently. There is clearly much we can learn from each other, and a great deal of improvement required to capitalize on the power of administrative data to answer important policy questions.

Appendix A: Survey

Data Access Review Times Survey

March 2012

The intent of this brief survey is to collect information from organizations responsible for research access to administrative data about timelines for access for research or evaluation purposes, and to understand what might influence these timelines.

A. Background:

1. Is the unit part of government, university, other? Please describe.
2. What functions and services does this unit provide? Indicate all that apply.
   - ☐ Access to data
   - ☐ Data linkage between internal data holdings only
   - ☐ Data linkage between internal data holdings and external data
   - ☐ Data analyses/ data aggregation

   What other functions are taken on? Please describe.

3. What body (and role within the body if an individual) adjudicates on applications for data?
4. Can non-"researchers" apply for data (e.g. people in government, hospitals, or industry)? If yes, are there different processes in place for this?
5. Are there geographical, institutional and/or other restrictions in terms of accessing the data?

B. Volume:

1. How many access requests do you receive in a year?
2. Roughly what percent involve data from more than one source?
3. Do you have a queue or backlog? If so, what is it?
4. Of your applications, roughly what percentage involve access to data at the individual level, and what percentage involve provision of aggregate results? Are there different processes in place based on the granularity of the data requested?

C. Timelines:

1. What is the average length of time (in working days if appropriate), for applications from initial application to data delivery? If possible, break down further into sub-categories. An example might be a) receipt of application to submission to data steward, b) data steward review to approval, and c) data approval to data extraction to delivery.

2. Is there much variation in times? If so, please give some examples of quicker than average and longer than average processing times.
3. What are the most significant factors affecting timelines? Indicate all that apply.
    a. Availability of the data
    b. Data steward reviews
    c. Responsiveness from researcher
    d. Complexity of the research project
    e. Uncertainty about privacy requirements
    f. Other, _____
4. Are researchers / your clients generally accepting of the application timelines?
5. Do you provide researchers with time commitments to receive data (i.e. from initial application to data delivery)? If yes, please describe.
6. In your view, what is an ideal (and realistic) timeline for application to receipt of data?

D. Cost recoveries:

1. Do you charge cost recoveries for your work? If yes, please describe, or attach your cost recovery policy / schedule, or provide a relevant link with information.

E. General:

1. What could be done to further improve the status of access to administrative data for research purposes, either in your jurisdiction or elsewhere?
2. Are there any other considerations you wish to share as it pertains to data access and application timelines?