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Access to routinely collected data for population health research: experiences in Canada and Australia

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In 2008, researchers at St Michael's Hospital in Toronto, Canada, demonstrated an association between neighbourhood walkability and the prevalence of obesity and diabetes.¹ They did so by linking the physician billing claims, hospital discharge data and residential postcodes for all residents of Toronto. They applied a validated algorithm to the physician claims and hospital data to identify people with diabetes and assigned a walkability index to each postcode. This revealed striking gradients, with relatively low rates of diabetes in the highly walkable central zones of the city and higher rates in the less walkable suburbs. This did not prove that poorly walkable neighbourhoods caused diabetes. A randomised trial to establish causality was not feasible. So, the researchers conducted a controlled cohort study where they measured diabetes incidence in more than 200,000 recent Canadian immigrants who were free of diabetes when they moved to different areas of Toronto.² After adjusting for age and socioeconomic status, they found the incidence of diabetes was 58% higher in immigrants who moved into the least walkable neighbourhoods, relative to with those who moved into the most walkable neighbourhoods. A weaker but still significant association between neighbourhood walkability and incidence of diabetes was found among long-term Toronto residents. These findings have influenced the design of new housing developments in Ontario.

Use of routinely collected health data in Canada

This diabetes mapping study arises from extensive experience of using routinely collected health data in population health

research in Canada. Researchers in Ontario and the neighbouring province of Manitoba have excellent access to population-level data, including primary care and specialist billing data, prescription dispensing claims, hospital discharge diagnoses, social service usage, vital statistics and census information, which can be enriched through linkage to electronic medical records, registries, surveys, laboratory data, Indigenous and immigrant status. All are linkable at the level of the individual.^{3,4} While many of the collections, particularly administrative (payment) data, lack key information such as body weight, clinical measurements and lifestyle factors these gaps can be filled to varying degrees by the information from electronic medical records, clinical registries and national surveys.

In Canada, studies like the diabetes mapping example are possible through national and provincial support for key developments including: i) robust and transparent governance of linked comprehensive population-level data, enabling timely approval of large programs of research generating hundreds of individual projects;^{5,6} ii) funding of data repository infrastructure that generates affordable marginal project costs;⁷ iii) validation of linked administrative data, and creation of algorithms and code sets that are shared across researcher groups;⁸ iv) the establishment of distributed networks of independent data centres conducting collaborative research of national importance, for instance the investigation of safety of prescription medicines;⁹ v) involvement of policy makers as knowledge users;¹⁰ and vi) broad public support for the use of personal health information for research by data institutes and university researchers.¹¹

A key success factor in Manitoba and Ontario was the establishment of dedicated independent centres where linked health data from the whole population are used to study a wide range of health problems. The Manitoba Centre for Health Policy (MCHP) and the Institute for Clinical Evaluative Sciences (ICES) act as secure stewards, making routinely collected data available in research-ready form to large numbers of researchers working within and outside the centres.^{12,13} Data are not released, and all analyses are done in a secure environment with external access through a virtual private network. The work has been enabled by legislation that allows the centres to work with linked unidentifiable data without the consent of the individuals involved. Crucially, the centres take on the responsibilities of the original data custodians, who are not involved in the approval of studies involving secondary uses of the data.

Both centres have strong data-sharing and governance agreements with many data custodians. Two national bodies, Statistics Canada and the Canadian Institute for Health Information (CIHI), share data to support external research. The former provides key census-derived data down to postcode level and conducts and shares data from regular comprehensive national surveys.¹⁴ CIHI develops and maintains data standards, and acts as a national steward of multiple provincial data-sets (and some registries), making them available in clean linkable research-ready form.¹⁵

Staff at the MCHP and ICES carry out validation work, including medical chart reviews at institutions across the provinces. The validation data, algorithms and code-sets are part of the intellectual property that is made available to everyone working with the data. Training is provided to analysts and epidemiologists, and at ICES there is a scholars' program for scientists.¹⁶ Many postgraduate research students complete the practical phases of their work in these centres. Both institutes conduct and facilitate a wide range of studies, including health and social policy analyses, health services research, public health research, pharmaco-epidemiology, health economics and clinical studies in areas ranging from mental health to chronic diseases and cancer. Examples of published studies are provided in the Supplementary File.

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Alberta, British Columbia, Quebec, Nova Scotia and Saskatchewan also provide access to high quality administrative data-sets.¹⁷⁻²¹ However, they do not have comprehensive integrated data and research centres, which subsume data custodian responsibilities to expedite the use of linked data-sets for research. Consequently, data access is often slower than in Manitoba and Ontario. The Canadian Institutes of Health Research (CIHR), Canada's national funding body for health research, recognised this challenge and in 2013 collaborated with the provinces to co-fund provincial data platforms as a feature of their national Strategy for Patient Oriented Research.⁷ This program mandated a high level of patient engagement in the planning and conduct of research projects. In another important example of infrastructure support, federal funding was used to establish the Canadian Network for Observational Drug Effect Studies (CNODES),⁹ a distributed network of data repositories, staff and scientists in seven Canadian provinces. CNODES leverages existing resources (including MCHP and ICES) and regularly performs multi-provincial analyses to address important questions about drug safety.^{22,23}

Comparison of routinely collected health data in Australia and Canada

There are similarities between the two countries. Both have comprehensive publicly funded healthcare systems that generate routine health data-sets documenting use of primary and specialist care, procedures, prescription medicines and hospital visits, and include a variety of registries.

But there are some key differences in the organisation of healthcare and hence data capture. In Canada, each province acts as a single payer for all health services and there is no private sector providing medically necessary care. The Canadian provinces have the lead role in providing both community and hospital-based services, including prescription medicines, although the extent of coverage of the latter varies by province. In Canada, health insurance claims often include a diagnostic code.²⁴ In comparison, Medical Benefits Schedule (MBS) claims data in Australia do not routinely include information on diagnosis.

In Australia, the Federal Government is directly responsible for the funding of primary care and specialist consultations and prescription medicines in the community,

while the states are responsible for hospital and clinic services, and there is a significant private sector. The central role of the Federal Government means that linkage of key data-sets requires cross-jurisdictional data-sharing, with the associated complexity and delays in project approvals. This is usually not necessary in Canada, with some exceptions, such as data that identify First Nations individuals and immigrants.^{25,26}

The publics in both countries appear to support broadly the use of routinely collected health data in health and medical research.^{11,27} In Australia, King and colleagues (2012) reported that 73% of survey respondents would agree to their medical records being used for medical research.²⁷ In the presence of 'extra security measures' a minority of respondents (25%) would feel some concern about threats to their privacy. In Canada, Willison and colleagues found that over 80% of survey respondents supported the use of their medical records for health research.¹¹ They expressed much greater trust in disease foundations, hospitals and universities than in pharmaceutical manufacturers and insurance companies.

Access to routinely collected health data for comprehensive health research in Australia

In Australia, the states govern the use of their own data and support a wide range of research studies. However, these often lack critical information that is only available from Federal Government data. Compared with the largely distributed processes that govern the use of linked whole-of-system health data in Canada, Australia has a more centralised data access process. The National Statistical Service (NSS) lays out the principles governing the linkage and use of Federal Government data.²⁸ Researchers must go through a demanding project-by-project process that includes the approval of data custodians.²⁹ By contrast, in Ontario and Manitoba, the MCHP and ICES subsume the roles of the data custodians of the linked collections; original data custodians are not required to approve individual projects arising from these linkages, making for a faster and more efficient approval process.

Historically, there have been only three accredited data integrating authorities in Australia; all are government agencies – the Australian Bureau of Statistics, the Australian Institute for Health and Welfare (AIHW) and the Australian Institute of Family Studies.³⁰

These organisations have important statutory and non-statutory roles and functions, which must limit their capacity to evaluate and respond to large numbers of requests for linked data for the purposes of external research.

Since 2009, the Federal Government has committed more than \$46 million to establish and support the Population Health Research Network (PHRN).³¹ PHRN has distributed funds to six state/territory data linkage units, one national accredited integration authority (AIHW) and a secure national remote-access data research laboratory, the SURE facility hosted by the Sax Institute in NSW. These centres are bound by the data access rules established by the Federal Government for use of its data, leading to slow project approvals.

Despite these challenges there have been excellent examples of innovative use of cross-jurisdictional data linkage, which are testimony to the tenacity of Australian researchers. Large cohort studies have used participant consent to access Federal Government health data. Examples are the Australian Longitudinal Study on Women's Health and the 45 And Up study.^{32,33} The Department of Veterans Affairs (DVA) acts as a single payer for the health care of its clients and, like the provinces of Canada, provides comprehensive data without the need for cross-jurisdictional linkage. The DVA has been pro-active in supporting research to improve the health and wellbeing of the veteran community and has helped establish pharmacoepidemiology as a research discipline in Australia.^{34,35}

At state level, the Western Australia Data Linkage System has been a pioneer in the use of linked data,³⁶ and this has sometimes included Federal Government data.³⁷ Data linkage units in other provinces have followed the WA lead, including the Centre for Health Record Linkage (CHeReL) in NSW³⁸ and the SA-NT DataLink facility for South Australia and Northern Territory.^{36,39} The SURE facility has established best practices in the independent stewardship of linked state and federal data.⁴⁰

In the face of these large investments the number of projects conducted in Australia using linked federal data remains very low compared to what has been achieved in other countries. A recent systematic review, led by one of us (SAP), cataloguing published studies using Pharmaceutical Benefits Scheme data from 1987 to 2013, found that

only 63 of a total of 228 studies involved person-level linkage to other data-sets, and many of these were conducted with data from the DVA.⁴¹

Most research activities with linked federal and state data appear to have been project-based rather than programmatic, leaving significant knowledge gaps and limited capacity development. Despite their best efforts, researchers have sometimes waited years to access the types of data that are available in a matter of days or weeks in other jurisdictions.^{9,42}

Productivity Commission Report on data availability and use in Australia

The recent Productivity Commission report on data access and use⁴³ and the Senate Select Committee Report on big health data⁴⁴ reflect these negative experiences.

Two comments in the Productivity Commission report suggest that attitudes and strict governance processes are a greater barrier to data access than existing legislation:

“Lack of trust by both data custodians and users in existing data access processes and protections and numerous hurdles to sharing and releasing data are choking the use and value of Australia’s data” and “Recommended reforms are aimed at moving from a system based on risk aversion and avoidance, to one based on transparency and confidence in data processes, treating data as an asset and not a threat.”

The Report recommends legal and structural changes to the framework that governs access to data in Australia. The main recommendations are summarised in Box 1. Of note, the Report recommends that accredited release authorities (ARA) take on the responsibilities of data custodians once they have linked the primary data-sets. Devolving this responsibility to data centres, as in Ontario, has been shown to be efficient and safe.⁴⁵

The Productivity Commission recommended a staged implementation. Some facets, such as legislative change and new or re-directed funding, may be slow. Others can be implemented much more quickly and should build momentum for sweeping change. Australians have already proven their ability to produce linked data research on a par with leading international networks. The logical next step will be to liberalise access to these data assets through creation

of Accredited Release Authorities. The most successful models are those where the equivalent organisations are independent of government and are mandated to support research across a broad range of subject areas.

Federal Government response to the Productivity Commission recommendations

The response was released on 1 May 2018.⁴⁶ The Government has committed \$65 million over the next four years to support Australia’s data infrastructure and plans to implement several of the main recommendations of the Productivity Commission. The Government will introduce a Consumer Data Right to provide consumers with greater control over the data that businesses hold about their activities. Governance of legitimate use of data (including de-identified health data) will be simplified and streamlined through new legislation that protects individual privacy. The Government plans to appoint a National Data Commissioner who will work together with the Australian Privacy Commissioner to oversee the new data access framework. The Data Commissioner will be assisted by a National Data Advisory Council, who will consult widely with community groups and provide advice on a range of issues including ethics and best practices in data privacy and security. Accredited Data Authorities will be established to determine which data-sets are made public, as well as who can access them.

Conclusions

Without question this is a positive response by Government. But we have one concern and one recommendation. Our concern relates to the governance of the Accredited Data Authorities, where the Government states that “accountability for the risks of sharing and releasing data will remain with data custodians”.⁴⁶ It is not clear exactly what this means. However, based on our extensive experience of working with routinely collected health data in Canada and Australia we believe that, if appropriate protections are in place, it is not necessary to involve the original data custodians in evaluating and approving proposed secondary uses of data. Once data have been shared through a secure mechanism and have been linked and de-identified by the Accredited Data Authority, decisions about downstream secondary uses should devolve to the appropriate oversight bodies concerned with privacy, science and ethics.

Finally, we recommend that the proposed Accredited Data Authorities should be independent of government. Government agencies inevitably have conflicting priorities and, in our experience, have difficulty attracting and retaining the necessary complement of highly trained data scientists and methodologists. Independent data research institutes like those in Manitoba and Ontario have the capacity to perform extensive analyses on behalf of government agencies, as well as to facilitate investigator-initiated research, program

Box 1: Principal recommendations of the Productivity Commission Report on Data Availability and Use.

1. A Data Sharing and Release Act (DSR Act): to provide a “one stop shop” for legislative requirements around digital data sharing and release, with a focus on access rather than transfer. It is intended to encompass Commonwealth, State and Territory, private and not-for-profit agencies.
2. Identification of National Interest data-sets*: for which all restrictions to access and use contained in a variety of national and state legislation, and other program-specific policies, would be replaced by the new national arrangements. These would be resourced by the Commonwealth as national assets.
3. Creation of a National Data Custodian (NDC): to accredit the processes and capabilities of a suite of Accredited Release Authorities (ARAs). The NDC would also publish guidance on data use for the benefit of ARAs and other data custodians and would assess for designation possible National Interest Data-sets.
4. Establishment of Accredited Release Authorities (ARAs): public sector entities/ agencies, other publicly-funded institutions or not-for-profit entities that have been accredited by the NDC and will be responsible for more complex, high risk data integration projects that individual data-custodians are unable to undertake. This will include the linkage and stewardship of National Interest Data-sets. The ARAs will take on the responsibilities of data custodians once the data are linked.
5. Designation of trusted users, who will be accredited by ARAs to access data under its control or governance. They may include any individual working in an entity that has in place the necessary data governance requirements to safely handle the data-sets in question and a signed legal undertaking that sets out safeguards for use and recognizes all relevant privacy requirements.
6. A streamlining of ethics committee approval processes would provide more timely access to identifiable data for research and policy development purposes.
7. Abolition of the requirement to destroy linked data-sets and statistical linkage keys at the completion of data integration projects.

Note:

* National Interest data-sets are characterised in a broad manner in the PC Report. Examples are large linked cross-jurisdictional data-sets that could involve aggregating data across the States and Territories in health, education, social welfare, child support, aged care, justice, linked to data-sets from other fields — e.g. the population census, taxation, employment, business ownership, telecommunications, private health insurance or housing.

and policy evaluations. The efficiency and innovation enabled by this infrastructure are beneficial to both the government and public. We need to achieve a critical mass of clinical and population health researchers, methodologists, data scientists, epidemiologists and analysts working together to address priority population health and clinical challenges with very large, heterogenous, multi-linked health data-sets. We believe that this is best achieved in a non-government environment in collaboration with academia.

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary Appendix 1: Examples of published studies that used routinely collected data in Manitoba and Ontario.

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