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## The McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

## About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-14 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

## About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on exploring data integration across sectors for public service improvement in Ontario. This brief includes information on this topic, including what is known about:

- the underlying problem;
- three possible elements of a comprehensive approach to address the problem; and
- potential barriers and facilitators to implement these elements.

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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# Key Messages

## **What's the problem?**

Integrating person-level data across sectors is viewed as an important step towards improving public services in Ontario. A number of benefits may result from better data integration, including: 1) providing a clearer picture of public service needs; 2) ensuring public services are citizen-centred; 3) improving efficiency; 4) facilitating better coordination of public services; and 5) leading to informed decisions that can improve social outcomes. Little emphasis has been placed on establishing sustained integration of data across sectors in Ontario. Additional challenges include worry among members of the public about privacy risks, a reliance on ad hoc data integration efforts, rather than sustained approaches over time, and a complex web of federal and provincial legislation that can be confusing and make it challenging to integrate data across sectors.

## **What do we know about three elements of a potentially comprehensive approach for addressing the problem?**

- **Element 1 – Establish a new set of policies that govern the integration of person-level data across sectors**
  - There is limited evidence about the pros and cons of developing new policies to govern data integration across sectors for public service improvement.
  - The evidence that does exist suggests that: 1) potential threats to policy development should be acknowledged; 2) little is known about whether there are benefits to inter-agency and/or inter-sectoral collaboration; and 3) while there is no one approach that is best for engaging members of the public in policy development, doing so may have benefits.
- **Element 2 – Ensure mechanisms are in place for continuous learning about the best approaches for integrating person-level data across sectors**
  - No evidence was identified about the benefits or potential harms of element 2.
- **Element 3 – Improve opportunities for members of the public to learn more about the processes and goals of data integration**
  - Although very little evidence was identified about the pros and cons associated with element 3, some evidence suggests that educating citizens and improving access to information is important for improving transparency and accountability.

## **What implementation considerations need to be kept in mind?**

Despite the number of barriers that exist, there are several facilitators that could help improve data integration across sectors in Ontario. These include (but aren't limited to): 1) there are many examples from other jurisdictions to learn from; 2) there is a common goal across government sectors in Ontario to improve public services; and 3) efforts to engage the public and work across sectors for public service improvement are likely to be supported.



Integrating person-level data across sectors in Ontario provides an opportunity to improve public services

## **The context:** Why a citizen panel on data integration?

>> There is a need to spark a public conversation about how to best leverage person-level data collected in Ontario in order to improve public services

### What are potential benefits of data integration?

Increasingly, policymakers, public-sector planners and researchers are acknowledging the interconnectedness of populations' social needs. Whereas in the past, individual needs were addressed almost exclusively within sectors (e.g., health problems were addressed in isolation by the Ontario Ministry of Health and Long-Term Care (MOHLTC)), it is now apparent that such needs are influenced by a variety of cross-cutting factors (e.g. health problems may be influenced by financial and environmental factors which are dealt with outside of the MOHLTC). Accordingly, demand is growing for the development of policies that address citizens' holistic and multifaceted needs, which require the input of multiple ministries and the broader public sector.

In Ontario, there are many ministries (and individuals or organizations providing services under the guidance from these ministries) that routinely collect person-level data that could, if integrated, provide a more comprehensive picture of population needs to policymakers and system planners. These include the Ministries of:

- Children and Youth Services;
- Citizenship, Immigration and International Trade;
- Community and Social Services;
- Community Safety and Correctional Services;
- Education;
- Environment;
- Finance;
- Health and Long-Term Care
- Municipal Affairs and Housing;
- Training, Colleges and Universities; and
- Transportation.

Integrating the datasets held by these ministries would provide opportunities to: 1) gain a better understanding of the interconnectedness of all public sectors in order to identify population service needs; 2) ensure that public services are truly citizen-centred (i.e. informed primarily by the real observed needs of citizens); 3) enable policymakers and planners to become more efficient at collecting data and conducting analyses; 4) assist in service coordination and enable the integration of public services; and 5) make better informed decisions that result in improved social outcomes. An integrated approach to data analysis can result in tangible benefits for citizens. Table 1 provides a summary of some of the potential benefits of better integrating person-level data in Ontario.

## Glossary (1)

### Person-level data

Information collected about individuals by the public sector when they interact with public services.

### Linkage

A merging that brings together information from two or more sources of data with the object of consolidating facts concerning an individual.(2)

### Data integration

The linkage and analysis of two or more databases using information that identifies the same person,(2) which may take place across datasets in a single sector (e.g. health) or across a number of sectors (e.g. health, education, environment).

### Personally identifiable information

Personal information (e.g. name, social security number, birth date) that can be used to connect data with the correct individual.(7)

### De-identified data

Data that has had all personally identifiable information removed to protect the privacy of individuals.(7)

**Table 1.** Potential benefits of data integration

Benefits	Explanation
<p><b>Provides a clearer picture of public service needs</b></p>	<ul style="list-style-type: none"> <li>• Linked datasets and the integration of data for analysis provide policymakers, researchers and social planners with a deeper understanding of the complex relationships that exist across sectors that are usually looked at in isolation                             <ul style="list-style-type: none"> <li>○ e.g. determining the relationship between education, health, use of social services, and poverty</li> </ul> </li> <li>• Researchers are able to make important connections between a diverse range of social factors over longer periods of time                             <ul style="list-style-type: none"> <li>○ e.g. determining whether poor educational outcomes for children and their risk of unemployment as adults are related to the age at which their mothers gave birth</li> </ul> </li> </ul>
<p><b>Ensures public services are citizen-centred</b></p>	<ul style="list-style-type: none"> <li>• Public services can be designed with the ‘whole’ individual in mind, rather than as clients within specific sectors, so that individuals’ broader public service needs are met                             <ul style="list-style-type: none"> <li>○ e.g. people are not patients only when using health services, or students only when in the education sector</li> </ul> </li> <li>• Policymakers, researchers and social planners can use integrated data to establish citizens’ real public service needs, and develop the most appropriate programs and services in response</li> </ul>
<p><b>Provides opportunities for improved efficiency</b></p>	<ul style="list-style-type: none"> <li>• Combines and uses information already routinely collected in each sector to provide new and novel insights, that costs less and is more reliable than developing new data-collection approaches</li> <li>• Minimizes the amount of information collected from clients and thus makes it easier for them to apply for or access services without having to re-enter or re-apply their basic information</li> </ul>
<p><b>Facilitates better coordination of public services</b></p>	<ul style="list-style-type: none"> <li>• Understanding how individuals use public services across all sectors provides opportunities for policymakers, researchers and social planners to improve coordination and transitions between, and integration of public services</li> </ul>
<p><b>Leads to informed decisions that can improve social outcomes</b></p>	<ul style="list-style-type: none"> <li>• Policymakers, researchers and social planners can make more informed decisions about how to improve the full range of public services and improve social outcomes                             <ul style="list-style-type: none"> <li>○ e.g. targeting early childhood education support programs for children who were born to mothers of a certain age, so that they can reach their full potential</li> </ul> </li> <li>• Better use of data will also enable policymakers, researchers and social planners to evaluate public services and identify those that benefit citizens most, so that the right programs and services are funded</li> </ul>

## What types of data integration are occurring in Ontario now?

Initiatives to integrate person-level data across sectors exist across Canada, while in Ontario most efforts focus on integrating information collected within the health sector for the purpose of health planning and policy development.

Nationally, Statistics Canada (StatsCan) and the Canadian Institute for Health Information (CIHI) have undertaken large-scale data integration projects. StatsCan has developed the Record Linkage program to support research activities by integrating data from four related databases (mortality, cancer, births and stillbirths).(8) This integration of data has enabled analyses exploring the relationship between ultraviolet light exposure and the development of cancer, as well as whether residing near industrial facilities may have an impact on mortality, among others.(9) Some of the linked files have been made available to researchers in secured settings, known as StatsCan Research Data Centres. Similarly, CIHI has developed what it calls its Clinical Administrative Database, which also links datasets to enable integrated analyses. This database links clinical data (e.g. the number of people diagnosed with the flu in a given period of time), demographic data (e.g. the ethnic make-up of the population in Ontario), and administrative data (e.g. the number of hospital beds in Windsor) to provide information that can inform funding, planning and evaluation.(10-11)

In Ontario, most initiatives focus on linkages between health-related datasets to support integrated analysis. For instance, the Institute for Clinical Evaluative Sciences (ICES) maintains a Data Repository, which links health data from government ministries and other sources (e.g. surveys), as well as information from other sectors (e.g. social services).(12) The integrated information held by ICES is widely acknowledged as instrumental in enhancing research, as well as supporting policymakers in making informed decisions about health system improvement. ICES has also been a leader in data integration across sectors, although this has largely taken place within the context of single research projects, rather than within efforts to directly inform the delivery of programs through sustained cross-sectoral data integration.

## What policies exist to govern data integration in Ontario?

In Ontario, there are two pieces of provincial legislation that are most directly related to data integration, with a particular focus on the collection, use and disclosure of personal information. These include:

- the Personal Health Information Protection Act (PHIPA, 2004) which establishes a legal framework for collecting, using and disclosing personal health information (PHI) by health information custodians (e.g. physicians, hospitals, the MOHLTC), and certain third parties who receive personal information from health information custodians<sup>(1)</sup>; and
- the Freedom of Information and Protection of Privacy Act (FIPPA, 1990), which provides a similar legal framework outside of health, and regulates the collection, use and disclosure of *any* type of personal information.<sup>(13)</sup>

These two pieces of legislation will be most important in shaping a potential framework for data integration in Ontario, in particular by safeguarding citizens' privacy.

In addition to PHIPA and FIPPA, there are other pieces of legislation that affect

### **Box 1: The Manitoba Centre for Health Policy (MCHP)**

Founded in 1990, the MCHP is a research unit at the University of Manitoba that focuses on the question 'what makes people healthy?' The centre developed and continuously updates a repository consisting of nearly 100 databases that contain de-identified data from administrative records of Manitobans. Anyone wishing to access these data requires approval from both the Research Ethics Board and the government's Health Information Privacy Committee. These databases include information on healthcare, education, social services and justice. Linking and facilitating the integration of data from a variety of sources, the MCHP is able to carry out high quality population-based research on health services, population and public health, and the social determinants of health.

Of the 92 major research projects taken on by the MCHP since its inception, 79 would have been impossible without the capacity to link databases. For example, by linking the Canadian Community Health Survey with health administrative data, the MCHP was able to examine trends in patients with chronic disease, specifically comparing the cost of healthcare for people who have these conditions to those who do not. These findings have informed policymakers and healthcare professionals about how to provide health services for patients with chronic diseases in a more cost-effective manner.

Over the years, the centre learned how to effectively construct and use linked datasets, forged relationships with policymakers across ministries which, although challenging, created opportunities to improve services for Manitobans using the insights gained.

data integration in Ontario. Different policy sectors are regulated by different pieces of legislation that provide frameworks for the collection, use and disclosure of personal information for certain groups in certain circumstances. For instance, the Youth Criminal Justice Act (YCJA, 2002) is federal legislation which governs personal information related to youth who come into contact with the justice system.<sup>(14)</sup> The existence of such sector-specific legislation will have an impact on the types of information within each sector that can be integrated, and how the linkage and integration of data is achieved. Furthermore, there are overarching laws at the federal level, such as the Privacy Act (1985), that ensures more than 250 federal government departments and agencies respect citizen privacy.<sup>(15)</sup> This type of legislation could have an impact on efforts to integrate person-level data collected by the federal government with that collected provincially.

## What can we learn from other jurisdictions?

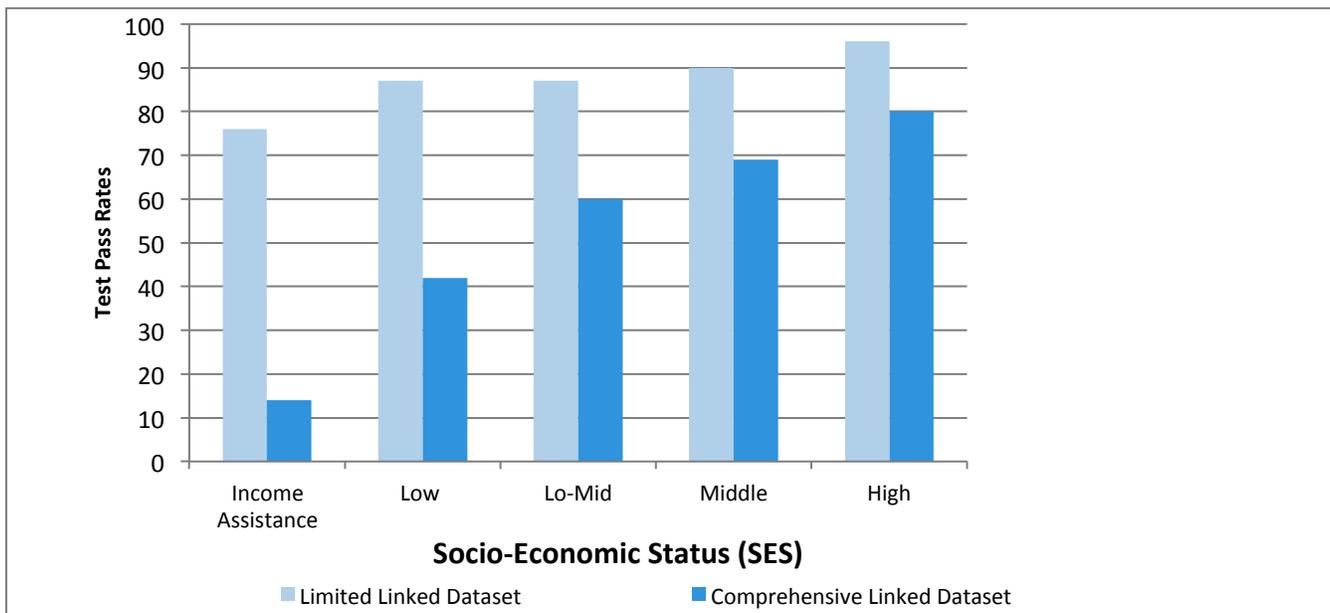
Other provinces in Canada and a number of countries around the world provide helpful examples of how to implement systematic and sustained data linkage projects that can facilitate better integration across sectors. In particular, Manitoba is a leader within Canada (see below and Box 1), while initiatives in Australia, Sweden and Wales are examples of international best practices for data integration (see Box 2 and 3).

The Government of Manitoba has implemented a sustained program, in partnership with the Manitoba Centre for Health Policy (MCHP), to facilitate the linkage of data from a number of sectors and the integration of these data to inform specific research projects. Through this partnership the MCHP conducts population-based research on health services, population and public health, and on how health is influenced by social factors (e.g. where a person lives or their economic status), in order to inform planning, monitoring and evaluation, and third-party research.<sup>(16)</sup> Box 1 provides an overview of the initiative.

An example of how this program has helped produce information that is valuable to policy planning comes from the education sector. Graph 1 below considers the relationship between household income (as measured using socio-economic status or ‘SES’) and a student’s pass rate on a 12<sup>th</sup> grade test. The light blue bars – which are based on a limited dataset that only includes information about socio-economic status and test results – show that the pass rate is relatively similar among low-, low-middle, middle- and high-income individuals. However, when these data are integrated with a more comprehensive dataset that includes information about absenteeism and other indicators about who should have

written the test (represented by the dark blue bars) a trend becomes clear: those from higher-income households have more success on the test.(17) Ultimately, this example shows that a more comprehensively integrated dataset can help to identify problems that a less comprehensive dataset may not be able to. It also has implications for the types of policy responses that are pursued. In this example, the first dataset may lead to no response, whereas the second integrated dataset may imply the need for strategies that provide targeted support to students in lower SES.

**Graph 1.** Insight from Manitoba: The “True” Story of Student Achievement (17)



**Box 2: International examples of data integration initiatives - The Western Australia Data Linkage System (WADLS)**

The WADLS was initiated nearly 50 years ago in Western Australia – an Australian state made up of mostly arid outback terrain. It started with a pilot scheme for medical record linkage in the late 1960s using personal identification numbers assigned to each individual in the population. It was expanded after 1995 to include information from a maternal and child health database (e.g. midwives' notifications, birth registrations, hospital outcomes and birth defects), and then to include data from the Western Australia Road Injury Database, which linked state-wide police, hospital and death records for road-crash casualties. Expansions since 2001 have linked personal information related to residential aged care, medical and pharmaceutical benefits, early-childhood development for vulnerable children (which provides insights from alcohol and drug services, education, health, disability and crime), and birth, marriage and death registrations since 1974 to link families across generations. The initiative also includes information related to residential addresses and electoral roll records, and there are plans to initiate even more linkages across education, community services and juvenile justice.<sup>(5)</sup> Integrating data over time from this wide range of sources has enabled researchers to address pressing health and social problems, and identify possible public health solutions.

**Box 3: International examples of data linkage initiatives – MigMed2 Database (Sweden) and SAIL (Wales)**

The **MigMed 2 Database in Sweden** contains person-level data going back more than 50 years. It is used to improve the government's ability to understand and address complex health and social issues in the country. The database contains individual-level information about all registered residents of Sweden and is linked across various sectors and databases with a single identification number assigned to each resident for his/her lifetime. The MigMed data includes each resident's age, sex, occupation, region of residence, hospital diagnoses, dates of hospital admissions, country of birth, parents' country of birth, date of emigration, and date and cause of death. It was constructed from several national Swedish registries including a population and housing census, a population and multi-generation register, as well as a hospital discharge register.(3)

**In Wales (U.K.)**, the Welsh government and the Swansea University Medical School have established the **Secure Anonymized Information Linkage (SAIL) databank**. The database is focused on conducting research to improve the service delivery of government health programs.(6) Access to the SAIL database is strictly monitored and granted only when there is clear potential for the research to provide public benefit. The Welsh government has taken a serious attitude towards citizen security by implementing a rigorous privacy framework, and by ensuring that any data utilized through SAIL is anonymized and untraceable, at the individual level. Currently, SAIL is facilitating research in a number of sectors, including neurology, children and young people's health, and mental health.



Approaches for collecting person-level data in Ontario were not designed with cross-sector integration in mind

## **The problem:** Why is it challenging to integrate data across sectors?

>> Taking advantage of the opportunities provided by integrated person-level data to improve public services and policy planning requires that integration initiatives across sectors are sensitive to the concerns of citizens while working within complex legislative arrangements.

## There have been few efforts to reassure the public about the protections in place to ensure their data are safe and secure

Some members of the Canadian public worry about increasing privacy risks as the digitization of their personal information (e.g. electronic health records) comes to be the norm.<sup>(18)</sup> Additionally, many people are unaware of how their personal information is being used, particularly in the context of research and in monitoring public service. People may also be concerned about additional issues, including:

- what the government knows and doesn't know about them;
- whether their use of public services is being 'tracked' through the system, and whether this influences their eligibility for benefits and access to programs and services;
- whether the information and data they are contributing to the system are being leveraged to improve public services;
- whether it is secured from 'hackers'; and
- who 'owns' their data, and whether it is protected from private companies or third parties who may want to access it for commercial reasons (e.g. to target advertising, or to determine eligibility for a private insurance plan).

While data integration initiatives in Ontario have extensive protections that ensure individuals' privacy and security, as well as the ethical use of their personal information, there have been no real attempts to educate the public about these measures in order to reassure them. For example, in the health sector both CIHI and ICES have extensive mechanisms in place to ensure personal health information is private (i.e. de-identified), secure and not misused. However, consent forms presented to those in the midst of contributing their person-level data serve as the primary source of information about these protections, with fewer efforts pursued to educate Ontarians more broadly, or engage them in conversations about how their data are used and integrated.

## Reliance on 'one-off' integration initiatives rather than systematic and sustained efforts has also created challenges

The integration of person-level data from across different sectors in Ontario has mostly been pursued as 'one-off' initiatives that are aligned to specific programs such as Ontario's

Poverty Reduction Strategy.<sup>(19)</sup> However, despite the promise of these efforts, there have been no sustained efforts to ensure this is done routinely.

One-off strategies are neither sustainable nor realistic in the long-term, and represent a missed opportunity to leverage information from across different sectors to better inform efforts to strengthen public services and achieve better social outcomes. As the examples provided earlier in this document illustrate, other jurisdictions in Canada and internationally have established approaches for linking datasets from multiple sectors in a sustained way with a view towards integrating a breadth of person-level data, and this is no longer viewed as ‘cutting new ground’. As such, Ontario is now lagging behind many others in efforts to utilize available data to improve public services.

One negative side effect of the reliance on ‘one-off’ approaches (i.e. ad hoc data integration) rather than on a more comprehensive and sustained approach to data integration, has been a separation between sectors over time. This separation between sectors means that data are being collected using different approaches and for different purposes. In some cases it may also lead to the duplication of efforts during program planning and implementation. For example, the health sector may gather information based on a person’s health card number, whereas other sectors may gather information using a person’s social insurance number, which is likely to complicate integration efforts.<sup>(2)</sup>

Another negative consequence of the historical separation between sectors is that there are now inconsistencies across sectors with respect to:

- capacity to collect and analyze data (with administrative structures in the health and education systems much better equipped than other sectors);
- technology (i.e. computer) support systems to manage and analyze data; and
- definitions of important factors that are of interest across settings and sectors (e.g. sectors may define poverty differently).

## Existing legislation and governance models further complicate the situation

As outlined earlier in this brief, there is a complex web of existing legislation – both provincial and federal – that affects person-level data linkage in Ontario. For example, while PHIPA provides the framework for personal health information collected and used within

the health sector, it is FIPPA that oversees the collection and use of person-level data for all other ministries and sectors. Furthermore, there are additional pieces of legislation at the federal level (such as the Privacy Act and the Youth and Criminal Justice Act), and at the provincial level (such as the Education Act) that also have implications for how person-level data are collected and used depending on the sectors involved. This overlap in policy frameworks may create confusion among those who are involved in designing and implementing data integration initiatives in the province, particularly when existing laws contradict each other. The various pieces of legislation also provide different restrictions on how ministries can share information with one another, which may complicate the government's ability to plan and evaluate programs in a holistic manner. Additionally, existing legislative frameworks were not designed to complement each other, or with a vision towards greater data integration across sectors. For example, PHIPA and FIPPA were established more than a decade apart within very different cultural, economic, political and social contexts – the latter was established in a time before the internet and digitized information sharing. As such, there are many instances in which these frameworks do not align, and speak to vastly different realities, particularly in the context of data linkage across sectors.

Finally, in contrast with many other countries (such as Wales and Australia), person-level data linkage initiatives in Ontario do not engage members of the public in providing input about the governance and oversight of person-level data integration. Research has shown a link between transparency and public trust, while concerns about privacy are more troublesome when people do not have confidence in the organization (or organizations) taking their information.<sup>(4)</sup> In Ontario, the lack of public engagement may contribute to privacy concerns because:

- the process is not open and transparent, increasing speculation about what the data are being used for; and
- there are no opportunities for the public to learn about the process, or to provide inputs about any concerns they may have with the process.



We have selected three elements of a comprehensive approach (among many) for which we are seeking public input.

## **Elements of a comprehensive approach:** How can we address the problem?

>> To promote discussion about the pros and cons of potential solutions, we have selected three elements of a comprehensive approach to data integration across public-service sectors in Ontario

Many elements could be selected as a starting point for discussion. We have selected three elements of a comprehensive approach (among many) for which we are seeking public input:

1. establish a new set of policies that govern the integration of person-level data across sectors;
2. ensure mechanisms are in place for continuous learning about the best approaches for integrating person-level data across sectors; and

3. improve opportunities for members of the public to learn more about the processes and goals of person-level data integration.

The three elements were not designed to be considered separately, and should be viewed as complementary. Specifically, elements 2 and 3 have been positioned as important supports for element 1. Additionally, it is important to consider that there are likely a number of other elements that could be considered, and new elements could also emerge during the discussions.

In the following sections, we provide a brief high-level summary of what is known about the pros and cons of each element based on the research literature. Additional details about the research literature that was identified by the authors when preparing this brief is provided in the appendix.

## **Element 1** – Establish a new set of policies that govern the integration of person-level data across sectors

While existing legislation regulates the use of person-level data within the health sector (PHIPA) and outside of the health sector (FIPPA), no policy framework exists to guide the integration of person-level data across sectors. It is clear from other jurisdictions that such an overarching policy framework is necessary to ensure successful data integration, while ensuring individual privacy and security. For example, the establishment and expansion of the Western Australia Data Linkage System (presented in Box 2), required the development of numerous policy agreements to facilitate integration across sectors.<sup>(5)</sup> Element 1 is in direct response to this need in Ontario, and could include the following components:

- engaging representatives from all public sectors who are interested in and willing to champion efforts to integrate person-level data;
- creating equitable opportunities for a broad range of citizens to inform policy development and governance related to data integration and use, by eliciting their diverse views, experiences and values;
- identifying opportunities to change existing legislation, or develop new legislation in order to facilitate better data integration across sectors;
- developing new policy tools within the scope of existing legislation, such as guiding principles and data-sharing agreements;

- setting clear targets and goals that establish expectations from new policy and regulatory frameworks;
- monitoring and evaluating each of the mechanisms to ensure they are helping to achieve targets and goals; and
- ensuring newly established policies can be updated and improved based on lessons learned from monitoring and evaluation.

The evidence about the pros and cons of developing new policies to govern data integration across sectors for public service improvement is very limited. The evidence that does exist suggests that:

- potential threats to successful policy development should be acknowledged (including having an unclear definition of the problem that is to be addressed, a lack of public support, opposing lobby groups, and poor enforcement);
- little is known about whether there are benefits associated with inter-agency and/or inter-sectoral collaboration in general, with no evidence in the context of data integration; and
- while there is no single best process for engaging members of the public in policy development, doing so may have some benefits (e.g. improving knowledge and awareness about the policy or program being developed) – although nothing is known within the context of data integration.

## Glossary (2)

### Health information custodian

A person or organization who has access to or control of personal health information as a result of performing their duties.(1)

### Re-identification risk

The risk that de-identified data will contain information that enables the identification of the individuals the data are linked to.(4)

### Privacy

The balance between collection and dissemination of data, technology and individuals' right to have their personal information kept private.

### Security

The policies and practices implemented at various administrative levels to ensure that data are kept safe from corruption, access is limited and appropriate, and that privacy is maintained by protecting personally identifiable information.(7)

### Confidentiality

The obligation of a person with access to another individual's personally identifiable information not to share it without consent.

## **Element 2** – Ensure mechanisms are in place for continuous learning about the best approaches for integrating person-level data across sectors

Element 2 includes various components designed to ensure that, once a new policy framework is put in place to guide data integration across sectors, every opportunity is taken to learn from experience and continually improve public services for Ontarians by strengthening the ways in which person-level data is utilized by decision-makers. With the goal of continuous learning, the following components could be considered:

- conducting ongoing reviews of what other jurisdictions are doing in order to learn about what works, what does not work and what this means for Ontario;
- engaging representatives from all public sectors to elicit their views about and experiences with data integration, and using this information to improve how data are integrated and used, while educating data users about what is and is not possible within the bounds of legislation; and
- engaging a range of members of the public to elicit their diverse views about and experiences with data integration, and using this information to improve how data are integrated and used.

No evidence was identified about the benefits or potential harms of element 2.

## **Element 3** – Improve opportunities for members of the public to learn more about the processes and goals of data integration

While some members of the public may be concerned about privacy and security in the context of person-level data integration, existing initiatives (and legislation) in Ontario place great importance on ensuring individuals' information is de-identified and protected, and any new initiatives would have to follow suit. However, members of the public currently have limited opportunities to gain a better understanding of how the full scope of their personal information is being used, and whether and how it is protected. Existing initiatives in the education sector, such as the Education Quality and Accountability Office (<http://www.eqao.com>) which aims to share information surrounding the administration

and analyses of student performance assessments with concerned members of the public, serve as an example of what is possible in the province. Element 3 includes a number of components that would constitute a similar approach for improving the transparency surrounding data integration and use across all sectors, including:

- creating an online hub that is tailored to members of the public, which provides one-stop shopping for information and resources related to Ontario’s efforts to improve public services through data integration across sectors;
- introducing a mechanism for concerned members of the public to ask questions about the data integration process, and to reassure them about privacy, security and ethical considerations; and
- identifying opportunities to proactively communicate details about data integration to members of the public (e.g. through newsletters and information sessions delivered at public service agencies, or within existing processes in which person-level data are being collected).

Although very little evidence was identified about the pros and cons associated with element 3, there is some evidence that suggests educating citizens and improving access to information is important for improving transparency and accountability.(20)

## **Implementation considerations**

It is important to consider what barriers we may face in implementing potential solutions. The three elements presented above will now be considered in the context of barriers. These barriers may affect different groups (e.g., citizens and public service providers), different public service organizations or the entire public sector. While some barriers could be overcome relatively easily, others could be so substantial that they force us to re-evaluate whether we should pursue that element.

Various factors could also facilitate the implementation of each of the three elements. A facilitator could be a recent event that was highly publicized in the media, a crisis, a change in public opinion, or an upcoming election.

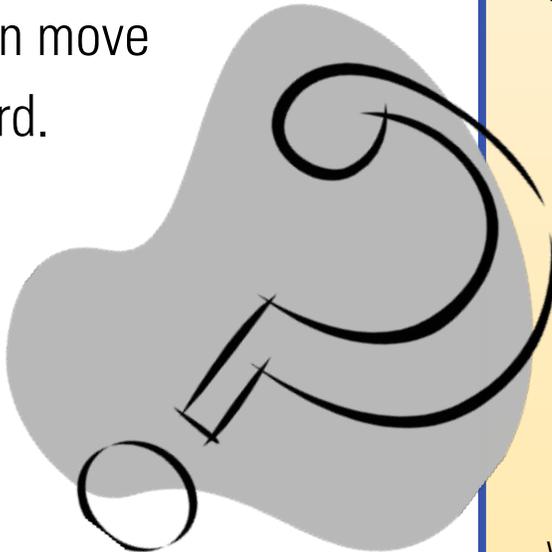
A list of potential barriers and facilitators for implementing the three elements is provided below. This table is provided to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have identified the barriers and

facilitators from a range of sources (not just the research literature) and we have not ranked them in any way.

<b>Element 1 – Establish a new set of policies that govern the integration of person-level data across sectors</b>	
<b>Barriers</b>	<b>Facilitators</b>
<ul style="list-style-type: none"> <li>Existing legislation is layered and complex, which may make it difficult to work within existing laws and regulatory frameworks</li> <li>It may be challenging to develop policies that stakeholders from all involved sectors agree upon, or that represent the full range of views and perspectives held by members of the public</li> </ul>	<ul style="list-style-type: none"> <li>There are many successful examples of multi-sector data integration frameworks from other jurisdictions – both within Canada and internationally – that Ontario can learn from</li> <li>A clear articulation of the benefits of integration to the public makes change more likely</li> <li>There is a common goal across government sectors in Ontario to improve public services and social outcomes while making things more efficient</li> </ul>
<b>Element 2 – Ensure mechanisms are in place for continuous learning about the best approaches for integrating person-level data across sectors</b>	
<b>Barriers</b>	<b>Facilitators</b>
<ul style="list-style-type: none"> <li>Public-service professionals and managers who are engaged in the collection, day-to-day maintenance and use of person-level data for decision-making may oppose this element (particularly if they view an effort to determine what works and what doesn't work as an effort to evaluate their performance, or have concerns about the misinterpretation of their data)</li> <li>Additional time would be required for staff working in government to continuously identify and incorporate best practices, and the potential for frequent change may be viewed as disruptive and inefficient</li> <li>It may be challenging to engage members of the public, particularly groups who do not feel equipped to provide feedback or have challenges in accessing engagement opportunities</li> </ul>	<ul style="list-style-type: none"> <li>Members of the public are likely supportive of an opportunity to provide feedback about their experiences as they relate to public services</li> <li>Conducting scans to learn from what other jurisdictions are doing is already common in many government agencies</li> </ul>
<b>Element 3 – Improve opportunities for members of the public to learn more about the processes and goals of data integration</b>	
<b>Barriers</b>	<b>Facilitators</b>
<ul style="list-style-type: none"> <li>Technical aspects of data integration initiatives may be challenging to communicate clearly with members of the public</li> <li>With many sectors involved, it may be difficult to determine who is responsible for ensuring the processes and goals of data integration are communicated and made transparent to the public</li> </ul>	<ul style="list-style-type: none"> <li>Members of the public are likely supportive of an opportunity to become better informed about how their data are being used to improve public services</li> <li>An inter-sectoral approach is likely to be more powerful in gaining public support</li> </ul>

## Questions for the citizen panel

>> We want to hear your views about the problem, three elements of a comprehensive approach for addressing it, and how we can move forward.



This brief was prepared to stimulate the discussion during the citizen panel.

The views, experiences and knowledge of citizens can make a great contribution.

More specifically, the panel will provide an opportunity to explore the questions outlined in Box 4. Although we will be looking for common ground during these discussions, the goal of the panel is not to reach consensus, but to gather a range of perspectives on this topic.

### Box 4 >> Questions for the citizen panels

In your opinion, what is the importance of data integration across sectors? What do you feel are some of the potential benefits to you?

In your opinion, what are our biggest challenges related to integrating data across sectors in Ontario?

What are your views about the three proposed elements?

>> **Element 1:** Establishing a new set of policies that govern the integration of person-level information across sectors

>> **Element 2:** Ensuring mechanisms are in place for continuous learning about the best approaches for integrating person-level data across sectors

>> **Element 3:** Improving opportunities for members of the public to learn more about the processes and goals of data integration

What would you consider to be the biggest opportunities (and biggest challenges) for moving forward with any one of the elements?

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## Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the citizen brief. The funder played no role in the identification, selection, assessment, synthesis, or presentation of the research evidence profiled in the citizen brief.

## Merit review

The citizen brief was reviewed by a small number of citizens, other stakeholders, policymakers and researchers in order to ensure its relevance and rigour.

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# Appendix

In the table below, we examine what is known about the benefits and harms of each option, by summarizing the findings of systematic reviews of the research literature. A systematic review is a summary of all of the studies addressing a clearly formulated research question. The authors use systematic and transparent methods to identify, select and evaluate the quality of the studies, and to summarize the findings from the included studies.

Not all systematic reviews are of high quality. We present the findings from systematic reviews along with an appraisal of the quality of each review.

- High-quality reviews: The methods used to conduct the review were excellent, and conclusions drawn from these reviews can be considered with a relatively high degree of confidence.
- Medium-quality reviews: The methods used to conduct the review were not very strong, and conclusions drawn from these reviews should be considered with some degree of caution.
- Low-quality reviews: The methods used to conduct the review were poor, and conclusions drawn from these reviews should be considered with a high degree of caution.

## Element 1 – Establish a new set of policies that govern the integration of person-level data across sectors

### What is known about **element 1**

- An older low-quality systematic review found that there were at least four threats to the success of new legislation: 1) problem misidentification; 2) lack of public support; 3) lobby group opposition; and 4) challenges with enforcement (21)
- While not focused solely on data integration, two recent and high-quality reviews,(22-23) and two relatively recent medium-quality reviews,(24-25) found that there was a lack of clear evidence showing the benefits of inter-agency and/or inter-sectoral collaboration both within the health sector and across a number of sectors, although one medium-quality review found that collaboration between primary care and public health could be beneficial (specifically for chronic disease, communicable diseases, and maternal and child health)(26)
- One old but high-quality systematic review,(27) and four medium-quality reviews,(28-31) were identified that focused on engaging members of the public across a range of policy development and planning initiatives, and while some found that doing so improved the public’s understanding and awareness of information about the policies and programs (and in some cases their ability to communicate about them), the evidence was unclear about other benefits or harms

**Element 2** – Ensure mechanisms are in place for continuous learning about the best approaches for integrating person-level data across sectors

What is known about **element 2**

- No directly relevant evidence was identified about the benefits or harms of introducing mechanisms for continuous learning, and one recent low-quality review was identified that found a lack of studies focused on stakeholder involvement in program monitoring and evaluation (32)

**Element 3** – Improve opportunities for members of the public to learn more about the processes and goals of data integration

What is known about **element 3**

- Almost no evidence was identified about the benefits or harms of improving opportunities for members of the public to learn more about the processes and goals of data integration, with only one recent medium-quality review identified that suggested educating and training citizens about services while improving access to information is important for improving transparency and accountability (20)





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