PANEL SUMMARY

INTEGRATING DATA ACROSS SECTORS FOR PUBLIC SERVICE IMPROVEMENT IN ONTARIO

23 JANUARY 2016
27 FEBRUARY 2016
5 MARCH 2016

EVIDENCE >> INSIGHT >> ACTION

McMaster Health Forum
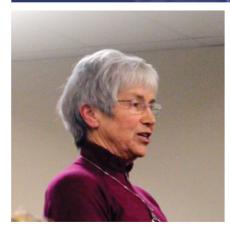
For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders and 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 10-16 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 summary

On each of January 23 (Hamilton), February 27 (Ottawa) and March 5 (Sudbury) 2016, the McMaster Health Forum convened a citizen panel on how to integrate data across sectors for public service improvement in Ontario. The purpose of the panels was to guide the efforts of policymakers, managers and professional leaders who make decisions about our health system. This summary highlights the views and experiences of panel participants about:

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

The citizen panels did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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Summary of the panel

Participants first noted it was important to consider that data integration could be used both to provide comprehensive aggregate data for research, policymaking and planning related to public service improvement, as well as to ensure each individual's data can be integrated and accessible across service settings to enable person-centred services. Six challenges for integrating data across sectors in Ontario were identified by participants as the most pressing: 1) Ontario lacks a clear data integration vision, and there is limited public 'buy in' for data integration; 2) there is a lack of transparency with respect to how person-level data are used in Ontario; 3) some citizens lack confidence in the government and the broader public sector; 4) there are many inefficiencies in existing systems for collecting, managing and using person-level data; 5) the rapid pace of technological change creates additional challenges for data integration; and 6) political factors reduce opportunities for data integration.

As part of the deliberations about the elements of a potentially comprehensive approach, participants indicated that an element '0' should be pursued before element 1 – the development of a long-term vision for data integration in Ontario. This was discussed with emphasis on the values-related themes of transparency, accountability and trust. Participants generally supported all of the elements, with the majority indicating that element 1 was important and that action in this area should be taken as soon as possible, and many agreeing that a 4$^{\text{th}}$ element – rigorous monitoring and evaluation – should also be added to the approach. The values-related themes of public engagement, patient-centredness, transparency, accountability, trust, efficiency and flexibility/adaptability underpinned discussions related to the elements.

Six sets of barriers were identified to moving forward: 1) the costs associated with such a 'big ticket' approach, its technical complexity, and a perceived lack of expertise in government; 2) the likelihood of the initiative being sustained as governments change; 3) a general mistrust towards government; 4) a lack of existing 'buy in' for data integration from the public; 5) a resistance to changing current data integration approaches among some members of the public; and 6) a concern that currently nothing is being done and we might miss an opportunity for improvement with respect to data integration. However, two facilitators supporting change were also identified: 1) things are already beginning to change; and 2) the public has the ability to understand the benefits of data integration if done well.

"The people of Ontario cannot afford for this to be botched."

Discussing the problem: What are the most important challenges to integrating data across sectors for public service improvement in Ontario?

Participants in each of the three panels began their deliberations by reflecting on how the problems (and their causes) related to integrating data across sectors for public service improvement in Ontario were described in the pre-circulated citizen brief. In doing so, it became clear that most participants felt that one essential point of distinction was missing from the document, and that it was important to clarify this before proceeding. In particular, a number of participants in each panel noted (and the majority of participants agreed) that it was important to clearly establish that data integration can be considered as a means to serve at least two separate, but complementary, functions: 1) providing comprehensive aggregate data for research, policymaking and planning related to public service improvement; and 2) ensuring each individual's data can be integrated and accessible across service settings to enable person-centred services. Most participants felt that, while they didn't have the same interest and personal connection with the first function (data for research, policymaking and planning) as they did with the second (data for enabling person-centred public services), it was important to keep this distinction in mind during discussions. Where appropriate, this distinction was considered in light of the various dimensions of the problem that were raised.

Throughout discussions of the problem, six challenges for integrating data across sectors in Ontario were identified by participants as the most pressing:

1) Ontario lacks a clear data integration vision, and there is limited public 'buy in' for data integration;

> **Box 1: Key features of the citizen panel**
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> The citizen panel about integrating data across sectors for public service improvement in Ontario had the following 11 features:
> 1. it addressed a high-priority issue in Ontario;
> 2. it provided an opportunity to discuss different features of the problem;
> 3. it provided an opportunity to discuss three elements of a potentially comprehensive approach for addressing the problem;
> 4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
> 5. it provided an opportunity to talk about who might do what differently;
> 6. it was informed by a pre-circulated, plain-language brief;
> 7. it involved a facilitator to assist with the discussions;
> 8. it brought together citizens affected by the problem or by future decisions related to the problem;
> 9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
> 10. it aimed for open and frank discussions that will preserve the anonymity of participants; and
> 11. it aimed to find both common ground and differences of opinions.

2) there is a lack of transparency with respect to how person-level data are used in Ontario;
3) some citizens lack confidence in the government and the broader public sector;
4) there are many inefficiencies in existing systems for collecting, managing and using person-level data;
5) the rapid pace of technological change creates additional challenges for data integration; and
6) political factors reduce opportunities for data integration.

Each of these challenges is discussed in the following sections. As is the case throughout the panel summary, insights were drawn from, and synthesized across, all three panels (Hamilton, Ottawa and Sudbury), and reference to specific settings are only made in instances where the values, views and experiences held by participants were unique to a particular setting.

Ontario lacks a clear data integration vision, and there is limited public 'buy in' for data integration

Many participants noted early on in discussions about the problem that after having read the citizen brief and considering their own knowledge of the current situation in Ontario, they concluded that there was no vision, strategy or plan for improving data integration across sectors in the province (and if there was, it was not communicated to members of the public). A number of participants felt that this was a particularly pressing challenge because it meant that it was unlikely that any concrete actions could be planned and implemented, and even less likely that there would be improvements in the short, medium and long term. A number of participants also voiced their concerns about how the lack of a clear vision made it difficult to determine who is (or should be) taking the lead on coordinating efforts to improve data integration in Ontario, as well as which stakeholders should be involved. Additionally, some participants noted that this made it difficult for them to grasp who is (or should be) accountable for better data integration.

Another major issue that participants highlighted with respect to the lack of a clear vision for data integration was that it meant no targets or goals existed. A number of participants stated that targets and goals were vital for signalling what the province hopes to achieve with improved data integration across sectors, and also provides a framework with which to measure progress going forward.

Within discussions around the lack of a clear vision, a number of participants flagged – and the majority agreed – that public 'buy in' for data integration did not exist. Several participants stated that this was likely due to the fact that most people don't know about any plans for data integration. A number of participants also suggested that, if the general public did become aware of such plans, then the lack of a clear vision would reduce the likelihood that there would be widespread 'buy in' for data integration. Some participants suggested that the absence of clear targets and goals would only serve to worsen the situation, as members of the public would need to be informed about how government targets and goals would translate into clear benefits for them.

There is a lack of transparency with respect to how person-level data are used in Ontario

In addition to participants' concerns about the lack of a clear vision in Ontario, the majority of participants stated that they didn't know how the information currently collected about them by the government and the broader public sector was being used to inform research, policymaking and planning. Most participants couldn't recall any particular instance in which they were provided with information about whether and how their personal information would be used for these purposes when they were asked to provide it.

Furthermore, most participants didn't have a sense about whether and how their personal information was used by public service providers to improve their experience with public services. In particular, a number of participants provided details of their own experiences in the health system, where it was clear that there were inconsistencies in how their personal information was collected, managed and then used. Most participants with such experiences stated that they had little understanding of why such inconsistencies existed, but many suggested that they believed things could and should be done better.

Overall, there was a general consensus among participants that their personal information was going into a 'black box'. Some participants suggested that if this dimension of the problem was not addressed, it would exacerbate the lack of public buy in already discussed, and a number also indicated that they believed the lack of transparency in how their personal information was currently being used has contributed to the dimension of the problem that was discussed next – that many citizens lack confidence in the government and public sector.

Some citizens lack confidence in the government and broader public sector

While many participants expressed appreciation for the efforts of those working in government the public sector, a number stated they didn't have confidence in the public sector's ability to undertake and successfully implement 'big ticket' items, such as integrating data across sectors for public service improvement. The lack of confidence was expressed by participants in one of two ways: 1) in relation to those working in government generally; and 2) in relation to those who are responsible for managing and delivering public services.

The lack of confidence in government was described by participants as stemming from past incidents in which it appeared to the public as though the government was not working in interests of the public. Examples provided by participants to justify their opinions included the eHealth Ontario (a government agency) scandal in 2009, the cancelling of gas plants by the government in 2011, and the controversy surrounding the Ornge air ambulance company (another government agency) from 2011-2013. Some participants stated that this made government seem less trustworthy, and others pointed to these as examples of negligence. A majority of participants stated that, overall, these incidents had led to decreased confidence in the government's ability to deliver on promises. Some participants also felt that, even if they had confidence in government in general, they didn't feel government possessed the capacity and competencies required to plan and implement a project as ambitious as integration of data across sectors. Finally, while many participants agreed that they lacked confidence in government to some extent, they acknowledged that their opinions were shaped by the media, who tend to frame these stories in ways that tend to dramatize any shortcomings of government.

The lack of confidence in the public sector employees responsible for managing and delivering public services took the form of four specific concerns.

The first concern shared by a number of participants was the chance that public sector employees may misuse the personal data they have access to. One participant suggested that sensitive information in the hands of the wrong person could be used to invade the privacy of individuals, and one participant even used the example of blackmail as an illustration of this point. The second concern was that providing public sector employees with more information about individuals may result in unfair judgments of that person, which could affect how they are treated by service providers. The third concern shared by several participants was that, in addition to being judged and treated differently based on private

information, there was a risk that public sector employees may determine who gets access to a broad category of benefits based on personal information. One potential example of this provided by a participant was restricting access to certain prescriptions based on having a criminal record.

The fourth and final concern voiced by participants in relation to a lack of confidence in public service providers was that, there would be significant challenges clearly defining who has access to data, what they have access to, and what they can (and should) do with the data. This concern was voiced in relation to the complexity of considering all of the potential ways in which individuals working in the public sector could misuse the many different types of personal information that may be available to them if there was more integration. Furthermore, there was general agreement among participants that no matter how many rules and regulations were in place, all public sector employees were individuals who may or may not adhere to the rules and work in the best interest of citizens, so there would be challenges enforcing any ethical standards.

There are many inefficiencies in existing systems for collecting, managing and using person-level data

Inefficiencies in service settings were mentioned as a challenge by participants in all of the panels. In particular, many participants highlighted that existing systems for collecting, managing and using person-level data to inform a range of public services are problematic. Participants suggested that there were at least three reasons for the inefficiencies.

First, many participants stated that they experienced a lack of coordination between sectors. A number of participants used their outdated Ontario Health Insurance Plan (OHIP) card as an illustration of a failure to coordinate data collection across sectors leading to inefficiencies. In particular, a few participants who discussed this example wondered why there wasn't a system to flag for Service Ontario that their OHIP card needed to be updated when they went to renew their driver's licence so that both could be accomplished at once. A number of participants wondered why there was more than one card for each Ontarian, when things could be done more efficiently with a single number and card.

The second source of inefficiencies, related to the first, is the duplication of effort across sectors with respect to collecting and managing their personal information. A number of participants noted they felt frustrated that they are often asked for the same information

(e.g., address and postal code), when they interact with public service organizations, and wondered why this information wasn't housed centrally.

Third and finally, participants believed that the existing data collection systems in the public sector lacked the capacity to collect accurate and useful personal data. Several participants said that they had experiences with their information being collected incorrectly (e.g., their preferred name) which could be attributed both to the people collecting the information, as well as to the inflexible (and sometimes inappropriate) tools with which they collected the information.

While not an inefficiency per se, several participants also suggested that the costs associated with not doing anything should be acknowledged. Specifically, the participants who raised this issue pointed out that technological advances will eventually lead to a public sector that increasingly relies on digital information that can (and will) be integrated across sectors and settings. As such, proactively developing and managing these systems were suggested as ways to help ensure they work as efficiently as possible. A number of participants believed that doing nothing now and relying on reactive approaches in future will create additional costs to the public sector.

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants.

- **How many participants?**
  11 participants attended the Hamilton panel, 16 attended the Ottawa panel and eight attended the Sudbury panel

- **Where were they from?**
  Participants were from the regions covered by the Hamilton Niagara Haldimand Brant, Champlain and North East regional Local Health Integration networks

- **How old were they?**
  Nine participants were aged 25 to 44, 10 participants were aged 45 to 60, 10 participants were aged 61 to 70, and six participants were 71 or older

- **Were they men, or women?**
  15 participants were women and 20 participants were men

- **What was the income level of participants?**
  Seven participants earned less than $20,000, four participants earned between $20,000 and $39,999, 10 participants earned between $40,000 and $59,999, and eight earned between $60,000 and $79,999, while six participants preferred not to provide their income

- **How were they recruited?**
  Selected based on explicit criteria from the AskingCanadians™ panel

The rapid pace of technological change creates additional challenges for data integration

While the inevitability of technological change was discussed in the context of inefficiencies, the pace at which change is occurring was itself considered a challenge by many participants as well. In particular, a number of participants asserted that since technology is constantly changing, it is extremely difficult to design and implement an approach to integrating person-level data across sectors that will remain optimal over time. Those participants who mentioned this also noted that there were unforeseeable challenges associated with the rapid pace at which technology is changing. To illustrate this particular point, some participants noted that the relatively recent threat of computer hacking created by the internet and cloud computing was something many people couldn't have predicted 20 years ago.

Political factors reduce opportunities for data integration

A number of participants in all three of the panels highlighted the important role that political factors play in creating challenges. In particular, two political institutions were identified by several participants as establishing real barriers to pursuing better integration of data across sectors.

The first problematic institution is the existing web of legislation and regulatory frameworks that exist at both the provincial and federal levels. Many participants said that they viewed these as a challenge given they complicate things for those involved in thinking through how to move forward with data integration. However, it was also noted by a number of participants that this particular challenge was not top of mind for members of the public, so was not the most important issue to them.

The second problematic institution identified by several participants was the change in government brought about by regular election cycles. While many acknowledged that this is inevitable in a democratic society, some participants described changes in government as a threat to the long-term stability of any strategic plan to support data integration in Ontario. Specifically, some participants said that they worried that even if a non-partisan plan was developed, politics could interfere (e.g., a future government could do away with anything established by a former government).

There was broad agreement among participants that there is a need to develop a long-term vision for data integration in Ontario

Discussing the elements:

How can we address the problem?

After discussing the challenges that together constitute the problem, participants were invited to reflect on three elements of a potentially comprehensive approach for addressing the problems related to data integration across sectors in Ontario. Participants in all three panels indicated that there were some important steps missing in the approach taken to frame the elements in the citizen brief. In particular, many participants suggested the addition of a new element prior to element 1 (which many referred to as 'element 0'), as well as the addition of a new element 4. The sections below summarize the discussions of each element with a focus on the values underpinning participants' views.

(New) element 0 – Developing a long-term vision

Participants generally felt that there was a missing element that should precede the three that were outlined in the citizen brief, and many participants continually referred to this as 'element 0' to indicate its importance in laying the foundation for future efforts to improve data integration in Ontario. Participants suggested that this element should aim to articulate the long-term vision for data integration across sectors in Ontario, and clearly set out a strategy for achieving that vision. A number of participants also indicated that such an effort would assign responsibility for the data integration effort and place emphasis on clearly articulating the benefits of data integration to the public.

Three values-related themes were expressed in relation to this element:
1) trust (creating a shared vision for the initiative and ensuring the right people are involved would engender trust among policymakers, researchers and the public);
2) accountability (through clearly identifying who is responsible when data are being integrated from multiple sectors); and
3) transparency (by laying out a process and 'making the case' for why this is important).

There was general consensus that element 0 would be an important first step in laying the groundwork for data integration and, if done properly, could establish trust (the first values-related theme identified by participants in relation to this new element).

In relation to the notion of accountability (the second values-related theme to emerge within discussions of this new element), a number of participants mentioned the need to assign leadership for the initiative, since working to integrate data across sectors means there is no natural 'home' in government for it. Identifying appropriate leadership was important so that the vision could be clearly 'owned,' which would help to establish clear lines of accountability in relation to the proposed process and the outcomes. Participants raised several options for leadership models, including:
- creating a new 'Ministry of Data and Information;'
- hosting the initiative at a more 'impartial' government entity (e.g., the Ontario Auditor General or Ombudsman);
- contracting out to a third party (e.g., to a trusted crown agency, not-for-profit organization or a collective of well-known private companies with expertise in data integration); and

- creating a new entity for collective leadership comprised of professionals or experts in data and information, government representatives, and members of the public.

Regardless of the leadership model selected, participants broadly felt that members of the public should be very involved at this step, having an equal say at the decision-making table.

In relation to ensuring transparency (the third values-related theme discussed), most participants also felt that there was a need to set a clear vision that was 'big picture' in nature and would 'make the case' for the public about why data integration is important. Many participants suggested that within this element, a particular focus should be placed on ensuring the anticipated benefits for members of the public are clearly articulated. Many participants related this back to the problem of not having clearly articulated the function(s) of data integration (identified above), namely: 1) providing comprehensive aggregate data for research, policymaking and planning related to public service improvement; and/or 2) ensuring each individual's data can be integrated and accessible across service settings to enable person-centred services. A number of participants suggested that identifying a clear vision would be an important first step for getting citizens on board with the initiative and instilling confidence that the initiative was in good hands. This step would also help determine what was feasible and the funds needed to do it.

Most participants felt that while this element was an important opportunity for establishing trust, clearly assigning accountability, and making the process of data integration more transparent, this would be very difficult to do and many citizens would not pay attention to the issue until they encountered the outcomes of it in some way. Nevertheless, participants brainstormed several options for engaging the public and gaining buy in, including mass media campaigns, using social media, and taking advantage of existing infrastructure (such as Service Ontario locations) to educate the public.

> **Box 3: Key messages about (new) element 0**
> - Many participants stated that the (new) element 0 – developing a long-term vision – was essential to include in a new data integration initiative, and was missing from the existing elements in the citizen brief
> - The values-related themes that underpinned participants' views about this new element were:
>   - trust (creating a shared vision and ensuring the right people are involved);
>   - accountability (clearly identifying who is responsible for what); and
>   - transparency (laying out the process, and making the case for its importance)

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

Element 1 identified the need for a new set of policies to govern the integration of data across sectors as the existing legislative and regulatory landscape is not adequate for such an endeavour. The element included several components of a new policy framework for Ontario:

- engaging representatives from the public sector and a broad range of citizens in the process of development;
- identifying opportunities to change existing legislation or develop new legislation;
- developing new policy tools such as data-sharing agreements;
- setting clear targets and monitoring and evaluating them; and
- ensuring new policies are updated and improved based on feedback.

Four values-related themes emerged during the discussion about element 1:
1) public engagement and person-centredness (by ensuring citizens are at the centre of the new policy development processes);
2) transparency (by engaging all stakeholders, including citizens, in the development of new policies to govern data integration);
3) accountability (by establishing mechanisms within new policies to hold people accountable for misuse of integrated data); and
4) efficiency (by ensuring the experiences of other jurisdictions that have already developed comprehensive policies are leveraged to streamline the process in Ontario).

Overall, most participants were supportive of element 1, affirming the importance of ensuring public engagement and designing new approaches to data integration with the needs of the public front-and-centre (which was relevant to the first values-related theme). A number of participants indicated that they felt strongly about the need for the approach to data integration to be designed around citizens while keeping in mind each individual's unique needs, which would require that citizens be involved in the process of developing the new approach. Many participants recognized, however, that engaging a representative group of the public is very challenging to do well, particularly given they may already be jaded by past experiences of engagement. Additionally, some participants mentioned that getting consensus at the citizen level would be tough, and there could be some limits on the capacity of citizens to understand the problem and envision the solutions.

> **Box 4: Key messages about element 1**
>
> - Participants were generally supportive of this element, with the proviso that a long-term vision was developed in element 0
> - Four values-related themes emerged during discussion about element 1:
>   - public engagement and person-centredness (ensuring citizens are at the centre of the new policy development process);
>   - transparency (by engaging all stakeholders, including citizens, in the development of new policies to govern data integration);
>   - accountability (by establishing mechanisms within new policies to hold people accountable for misuse of integrated data); and
>   - efficiency (by ensuring the experiences of other jurisdictions that have already developed comprehensive policies are leveraged to streamline the process in Ontario)

While discussing element 1, participants also identified the need for the process to be clearly explained and deemed fair by the public, which suggests transparency was also extremely important (the second values-related theme to emerge within discussions of element 1). A number of participants also suggested the need for a wide range of opportunities for public participation at different points in time and at different levels. They also emphasized that the outcomes (i.e., a new approach to data integration) must clearly be framed in ways that indicate they are person- and family-centred. Finally, a number of participants reinforced the fact that the outcome of data integration efforts should primarily be improvements in public services and systems for the citizens of Ontario.

Many participants acknowledged the complexity of the task of developing a new approach to data integration and implementing it, which they felt increased the need for clear accountability (the third values-related theme to emerge in discussions about element 1). Some participants expressed concerns about accountability, particularly as they related to changes in government and shifts in the governing party. A number of participants mentioned that this initiative should not be put at risk as a result of such routine changes, and that accountability must rest with everyone in the province (including all political parties) over the long term, in order to make it a success.

Participants also acknowledged that accountability may be a challenge given the technical complexity of data integration. Specifically, many participants felt that the private sector or a third party outside of government (e.g., a crown agency with expertise) should be very involved in the process, given it is unlikely the government could effectively manage a new approach to data integration on its own. Many participants stated that the need to source capacity and expertise outside of government would further complicate challenges related to establishing clear lines of accountability.

Additionally, some participants expressed the need to ensure that data were being used responsibly by all who have access to it. Some participants mentioned that the opportunity for mismanagement or misuse was high, so the legislation and other policies developed as part of a new approach to data integration must include safeguards to protect the data. Protections built into legislation and other policies were considered at a number of levels by participants: at the level of technical infrastructure, participants considered a system that limits the amount of integrated data that any one individual or service provider can view, while at the individual level, participants considered training service providers on what is appropriate use and misuse of integrated data. Many participants felt that legislation and other policies must specifically address instances of breaches and enforcement to ensure ongoing integrity of any type of system that is developed.

Finally, a number of participants emphasized that the establishment of a new approach to data integration needed to be efficient (which was the fourth values-related theme to emerge in discussions about element 1). They expressed this concern in relation to two features: bureaucratic inefficiencies, and inefficiencies associated with the timing of any new data integration initiative.

In terms of bureaucratic inefficiencies, some participants expressed a concern that the process of developing a new data integration approach in Ontario could become consumed by 'bureaucracy', and that this would limit the ability to move forward. Others felt that there was no need to start from scratch and that there should be some efficiencies gained by learning from what other jurisdictions have done, and by building on what are considered their 'best practices.' Building on the lessons about what worked for other jurisdictions was considered by a number of participants as a way to potentially overcome some of the inefficient bureaucratic processes that would be associated with starting from scratch.

In terms of potential inefficiencies related to the timing of such an initiative, some participants felt that it would be cheaper to move forward with this immediately rather than waiting, although others expressed concerns about the potential for cost overruns. A number of participants felt that waiting too long would result in additional costs, including the costs that would accrue if Ontario retained the existing inefficient system, as well as the costs that would be required to fix the system in the future after the technological and data landscape had evolved significantly. While many participants acknowledged the potential efficiency gains of moving quickly towards more integrated person-level data, a number noted that a viable strategy might be to proceed step-wise and aim for a well-functioning, partial integration of some data as a first step. These incremental changes could result in large efficiency gains for the system. Finally, most participants felt that any new policies or legislation and other policies must be flexible and adaptable to address the fast pace of technological change and ensure efficiencies can continually be achieved in the future.

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

Element 2 set out a goal of continuous learning during the course of ongoing implementation of any new data integration effort that is adopted. Three specific components were included in this element for consideration: 1) continuing to look outside of Ontario at other data integration efforts to learn from other jurisdictions; 2) engaging people from the public sector who are involved in the collection, management or use of integrated data and asking for their feedback; and 3) engaging members of the public to understand their experiences with public services (particularly as it relates to their data). Feedback from these sources would be used to continually improve the system.

There were two values-related themes that were identified in relation to this element:
1) flexibility/adaptability (given any new data integration efforts would need to allow for changes and modifications to be made as new lessons are learned); and
2) public engagement and person-centredness (reinforcing the value of eliciting feedback from members of the public to be used to inform improvements).

Most participants were supportive of this option, particularly given that they felt it is an important part of remaining flexible and adaptable (the first values-related theme) in the context of constantly changing technology and 'data integration landscape.' Some participants also felt that this was a good way to support an incremental approach, where data integration efforts begin with certain targeted areas and are then expanded out to all sectors over time (also discussed in element 1).

However, some participants felt that the flexibility and adaptability provided through a continuous learning process offered the advantage of being able to move forward using a 'big bang' approach, and that the government should "just get going with it." A few participants acknowledged that even with an incremental approach, technology has a life cycle and the process should anticipate this, which also helped establish the importance of integrating processes for continuous learning. They felt that at some point the system underpinning the data integration effort would need to be "re-evaluated and revamped instead of just tweaked." Other participants noted that many of the problems this effort will likely encounter could not be anticipated in the planning stages. As such, the process should proceed fairly rapidly to roll-out, but be flexible enough to adapt to problems identified after it is operational.

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Many participants also noted that the process of continuous learning was a good way to continue to engage members of the public (the second values-related theme identified in relation to element 2). Some participants stated that this element was particularly important for building trust between citizens and those leading the initiative, while a number of others noted that the process of soliciting responses and getting feedback from citizens would help educate them on the effort, and improve their understanding of the vision for the data integration initiative. However, some participants worried that the type of feedback provided by the public would not be valued equally to that of other stakeholders, and suggested processes be established to ensure it is a key input to ongoing system improvements. Additionally, there was a sense that the information collected through the process of continuous learning must be tied to action in order to maintain the trust of the public.

> **Box 5: Key messages about element 2**
>
> - There was almost unanimous support for element 2 and participants could articulate clear benefits arising from a continuous learning approach
> - Two values-related themes emerged during the discussion about element 2:
>   - flexibility/adaptability (given any new data integration efforts would need to allow for changes and modifications to be made as new lessons are learned); and
>   - public engagement and person-centredness (reinforcing the value of eliciting feedback from members of the public to be used to inform improvements)

In addition to the options for continuous learning identified, some participants indicated that they believed industry experts should be included as an additional source of feedback in this element, beyond those articulated in the citizen brief (which included 'representatives from all public sectors' and 'members of the public' as key sources of feedback).

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

Element 3 focused on ensuring efforts were in place to provide members of the public with access to information, in a variety of formats, about how person-level data are integrated and used in Ontario.

Three values-related themes emerged within discussions related to this element:

1) transparency (by making the process of data integration visible to members of the public and being clear about its goals and targets);

2) accountability (through efforts that establish the government's accountability for the initiative by addressing privacy, security and ethical concerns); and

3) efficiency (as it relates to potentially wasted resources if members of the public don't use the information provided to them about data integration).

Participants were mostly supportive of this option, and several different types of potential approaches to achieve this were considered, including:

- creating an online hub to act as an information resource
- finding opportunities to communicate proactively with the public (e.g., through mass media campaigns and leaflets inserted into government mailings); and
- ensuring information is provided when citizens are most likely to be open to thinking about data integration (e.g., providing more information about data integration at Service Ontario kiosks).

They also felt that these efforts should be tailored to a non-specialist audience, given that the highly technical components of this initiative could be challenging to communicate to a lay audience. They recommended that the language used be "simple" and "bite-sized," and that communications be sensitive to various language, cultural and disability groups.

In general, participants stated that they believed this element was an important mechanism for demonstrating the government's ability to be transparent (the first values-related theme to be considered with respect to element 3) while establishing accountability to its citizens through greater education about what the government is doing with personal information (the second values-related them to be considered). Participants also stated that providing participants with information in a variety of formats could be considered a vehicle for improving the awareness about (and establishing transparency related to) the vision for data integration. Some participants suggested that public support for the initiative could grow if some of the communications focused on describing early successes with data integration.

> **Box 6: Key messages about element 3**
> - Participants were mostly supportive of this element and generated several ideas on how to do this
> - Three values-related themes emerged during discussions about this element:
>   o transparency (by making the process of data integration visible to members of the public and being clear about its goals and targets;
>   o accountability (through efforts that establish the government's accountability for the initiative by addressing privacy, security and ethical concerns); and
>   o efficiency (as it relates to potentially wasted resources if members of the public don't use the information provided to them about data integration)

Several challenges were also identified by participants in relation to element 3. Many participants discussed the challenge of ensuring messages are articulated clearly enough for all of those who may seek information, and wondered how it would be possible to communicate something so complex to the general public, which could threaten the ability of this element to ensure both transparency and accountability. Others were skeptical that people would actually attend to the information provided, suggesting that certain people don't care about such issues until they perceive it to be something that directly affects them. This sentiment was considered by many participants as a potential source of inefficiency (the third values-related theme to emerge within discussion of element 3), particularly given that the large investments of time and other resources needed to support this type of public engagement could be wasted if the information wasn't used.

(New) element 4 – Rigorously monitor and evaluate of person-level data integration efforts

In addition to the three elements originally presented in the citizen brief, and the new element 0 identified above, participants identified a fourth element to consider – rigorous monitoring and evaluation – which most participants stated was different than continuous learning and adaptability. Specifically, some participants indicated that they felt this element was much more aligned with determining whether the person-level data integration initiative is meeting the goals and targets set out in the

> **Box 7: Key messages about (new) element 4**
>
> - Participants stated that in addition to the other elements considered, there is a need for rigorous monitoring and evaluation of a new approach to data integration
> - A number of participants suggested that monitoring and evaluations ought to be viewed as different than continuous learning because it is more outcome-oriented
> - The values-related theme of accountability underpinned participants' views about the need for this new element

vision, as identified in element 0. Whereas element 2 (continuous learning) focused on feedback cycles leading to continual improvements the implementation of a new data integration initiative, this element could be more outcome-oriented, and focus on whether the efforts are leading to their intended effects overall. One participant described continuous improvement efforts as continually "looking outward to the world" and finding ways to improve what is happening, whereas evaluation efforts are a way to "look in and reporting to the public on what we found." This new element was primarily associated with the values-related theme of accountability, which was also considered important in most of the other elements discussed.

Considering all of the elements together

While the discussion at each of the citizen panels in Hamilton, Ottawa and Sudbury differed somewhat in tone, there were no notable regional differences in perspectives. Overall, when the three elements were taken together, most participants felt confident that these were necessary but not sufficient elements of a comprehensive approach to person-level data integration for public service improvement in Ontario. They identified two additional elements that they felt would complement the existing three and enhance the opportunity for making the data integration initiative a success:

1. developing a long-term vision for data integration in Ontario that would precede the existing elements and be a necessary first step in laying the groundwork for the process and identifying the goals of integrating data, as well as involve the important task of assigning leadership and accountability for the initiative; and

2. rigorous monitoring and evaluation of person-level data integration efforts, which was seen to be separate from continuous learning, and focused on determining whether the person-level data integration initiative is meeting the goals and targets set out in the vision, and reporting back to the members of the public.

"This is a historical march – whether we like it or don't, it is going to happen."

Discussing implementation considerations:

What are the potential barriers and facilitators to implementing these elements?

After discussing the three elements of a potentially comprehensive approach for integrating data across sectors for public service improvement in Ontario, participants briefly examined potential barriers to and facilitators for moving forward. There were six sets of barriers that were identified. The first barrier identified was the cost associated with such a 'big ticket' approach, including the acknowledged technical complexity of such an undertaking and a perceived lack of technical expertise in the government to lead it. Second, participants acknowledged that there were many uncertainties associated with regular political changes, and specifically, many questioned the likelihood of the initiative as governments change over time. Third, participants' discussions highlighted that there was a general mistrust among members of the public towards government, stemming from past scandals, which has since led to a perception among many that the government cannot manage large initiatives in a cost-effective fashion. Fourth, participants flagged the current lack of 'buy in' for data integration from the public and the challenge of communicating with the public about real trade-offs related to integrating person-level data. Fifth, participants felt that the initiative might encounter resistance to change from some members of the public, and that

attempts to overcome this resistance might be perceived as a political campaign. Sixth and finally, participants noted that despite the fact that things are already happening rapidly in terms of integrating and using person-level data in other parts of our lives (e.g., the private sector and social media), we are currently doing nothing to support service improvement in the public sector by integrating data. This failure to act was noted by a number of participants as something that would likely present barriers to future efforts, given the task of getting province up to speed will become increasingly difficult the longer we wait.

Participants then turned to two factors that could facilitate efforts to implement person-level data integration in Ontario. The first factor that participants identified as a major facilitator was the sense that things are already changing, alongside what they stated was a strong sense of inevitability (i.e., a view that this is going to happen anyways). Given these facilitating dynamics, many participants believed that this initiative should move forward very soon, and most participants expressed their ultimate support for moving ahead, saying "if it is going to benefit us, go for it," or suggesting the government "get ahead of it," and "yes, it is inevitable, but let's make sure it is done right and takes all populations into account." The second major facilitating factor identified by participants was the ability for the public to understand the potential efficiency gains that could arise from integrating their person-level data. Specifically, many participants spoke about existing redundancies that exist across government information systems, such as the need to repeat the same basic information at each service juncture, or completing forms that required the same information, but were framed only slightly differently. They also referred to some positive examples of where data have been integrated to their benefit (for example, shared electronic medical records between the hospital and their primary-care physician). They felt that if done well, integrated person-level information would make their lives easier and make systems more effective and efficient.

Acknowledgments

McMaster University

McMaster
HEALTH FORUM

>> Contact us

McMaster Health Forum
1280 Main St. West, MML-417
Hamilton, ON Canada L8S 4L6
Tel: +1.905.525.9140 x 22121
Email: mhf@mcmaster.ca

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