

Ontario's Civic Engagement Strategy Advisory Report

MINISTER'S PATIENT AND FAMILY ADVISORY COUNCIL (MPFAC)'S
CIVIC ENGAGEMENT STRATEGY WORKING GROUP

Table of Contents

A Message from the Chair, Betty-Lou Kristy	3
Working Group's Expertise, Focus, and Passion	4
Executive Summary	5
Background	6
Civic Engagement: Giving Voice to People	7
Data for Good: Ontario's Transparency Centre	10
Ontario's Health Data Civic Assembly	12
Proposed Next Steps	16
Appendix A: Patient, Family, and Caregiver Declaration of Values for Ontario.....	17

A Message from the Chair, Betty-Lou Kristy

Health touches every aspect of our lives. We now know that wellness extends beyond health care to include the social determinants of health and social services more broadly. It is more important than ever that we work to humanize care by providing people the space to share their lived/living experience and health journeys to be the driving force behind health care transformation.

It has been an honour to serve as Chair of the Civic Engagement Strategy Working Group, a time-limited working group of the Minister's Patient and Family Advisory Council (MPFAC). I cannot stress enough how skilled, professional, and insightful my fellow members are – their lived/living experiences, expertise, and voices are essential to driving the meaningful change needed to realize the potential of this important work.

For the last four months, I have been in constant awe of the passion and commitment the Working Group has shown in co-designing this Civic Engagement Strategy. The Working Group hopes to help foster public trust and increase health data literacy across the province. On behalf of the Working Group, I am honoured to submit this advisory report to the Ontario Health Data Council and the Minister of Health. We are excited to continue to contribute to the future development and mature stages of the civic engagement work.

As a Working Group, we explored opportunities to increase health data transparency and promote health data civic engagement. Although we have identified two initiatives—a Transparency Centre and Health Data Civic Assembly—that will help launch an inclusive public dialogue on health data, we are mindful that civic engagement is an ongoing effort. Fundamental to this effort is a sustained commitment to ensure that the diverse voices of Ontario are always reflected in and remain at the very heart of health data strategy and policymaking.

Ontario must acknowledge health data barriers, risks, and historical harms upfront and ensure that health data is used to help and not harm. Moreover, we must collectively work together to build accessible, safe, and authentic spaces for people to discuss and learn more about health data and why sharing health data is important. We must harness this opportunity to attract Ontarians to be actively involved in government decision-making and foster a more civically engaged public.

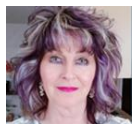
I would like to extend my sincerest gratitude to the exceptional members of the Working Group: Amandeep Kaur, Dean Valentine, Don Mahleka, Kimberly Cato, Sandi Bell, Shannon McGavin, Shequita Thompson-Reid, and Wendy De Souza. Their work speaks to the true power of patient, family, and caregiver voices in ensuring that data drives better, more equitable health care for all.

Betty-Lou Kristy
Civic Engagement Strategy Working Group, Chair
Minister's Patient and Family Advisory Council, Chair

Working Group's Expertise, Focus, and Passion

"A mantra underpinning groups like patient and family advisory committees with health organizations is something like 'nothing for us/about us without us.'"

~Civic Engagement Strategy Working Group Member, 2022



Betty-Lou Kristy (Chair): Childhood Trauma, Domestic Violence, Substance Use/Addiction, Mental Health, Bereavement, Cancer, Chronic Disease, Restorative Justice, Peer Support, Housing, Governance, Engagement & Co-Design



Amandeep Kaur: South Asian Community, Substance Use/Addiction, Mental Health, Marginalized and Diverse Populations, Leadership, Strategic Visioning, Community Development, Health Promotion, Chronic Disease Prevention



Dean Valentine: Veteran of Canada's Royal Canadian Navy, HIV/AIDS, Mental Health, Substance Use/Addiction, Harm Reduction, Community Building, Peer Support, Engagement, Governance, Human Resources, Research, LGBTQ2I Advocacy



Don Mahleka: Refugee from Zimbabwe, Chronic Pain, Trauma, Mental Health, Health Equity, Anti-Racism, Anti-Oppression, Youth Program Development, Change Management, Participatory Research, Policy Development



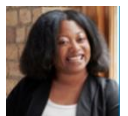
Kimberly Cato: Former Ordained Minister and Chaplain, Vision/Hearing & Mobility, Trauma, Mental Health, Body Image Issues, Life Altering Chronic Pain, Equity, Anti-Racism, Children In Care, Youth, Seniors, Palliative Care, Justice



Sandi Bell: African-Canadian/Indigenous, Human Rights, Social Justice, Anti-Racism, Anti-Oppression, Mental Health, Child Welfare, Education, Youth, Accessibility, Disability Issues, Equity, Diversity, Access, Inclusion, Mediation, Training



Shannon McGavin: Over 25 Years in Education Field, Rural Communities, Youth and Community Wellness, Mental Health & Substance Use, System Change, People Centred Teams, Transformative Change, Research, Health Standards



Shequita Thompson Reid: Racialized Communities, Equity and Anti-Oppression, Anti-Black Racism, Trauma, Mental Health, ADD/ADHD, Youth Engagement, Housing, Conflict Mediation, Violence Prevention, LGBTQQIP2AA, Education



Wendy De Souza: Intersectional Feminist Lens, Equity, Decolonizing Institutional Spaces, Gender Based Violence, Human Trafficking, Research, Complex Birth Issues, Mental Health & Addiction, Two Spirit, Nonbinary and Trans Communities

Executive Summary

Today, health is no longer simply defined as an absence of illness. Instead, health comprises the social determinants of health that shape a person's overall well-being and quality of life. Given this broader and continually expanding definition of health, the topic of collecting, using, protecting, and sharing health data is an extremely personal one. There is a growing need to engage the public in widespread, sustained, and inclusive dialogue about their health data.

A Joint Ministers' Roundtable (JMR) for Ontario's COVID-19 Health Data Platform, the Ontario Health Data Council (OHDC), and the pan-Canadian Health Data Strategy Expert Advisory Group (PCHDS EAG) published reports¹ identifying ineffective health data literacy, public engagement, and transparent reporting as key barriers to achieving a person-centred health system. They recommend that Ontario empower, educate, and engage the public—including Black, First Nations, Inuit, and Métis (FNIM) peoples, Francophone, racialized communities, and vulnerable populations—on health data to foster public trust, which is foundational to sharing data for good.

In 2022, the Ontario Health Data Council (OHDC) laid out a vision for ensuring the public's health data needs and interests remain at the centre of Ontario's future health system. To help realize this vision, the OHDC and the Minister's Patient and Family Advisory Council (MPFAC) co-sponsored a time-limited MPFAC Civic Engagement Strategy Working Group (CESWG) to develop an equitable and inclusive province-wide civic engagement strategy. Tasked with enhancing data literacy, creating opportunities for sustained engagement, and fostering public trust, the CESWG met between February 2023 and June 2023 to discuss opportunities to help promote a deliberative data democracy and improve the health of everyone across Ontario.

This report outlines the recommendations of the Working Group, which include:

1. A **Transparency Centre**: launch a free, one-stop hub for the public that cultivates health data literacy and trust, acknowledges data barriers and harms, fosters more open dialogue on health data issues, and promotes data sharing data for good.
2. A **Health Data Civic Assembly**: build a distinctions-based, intersectional, trauma-informed, and bi-directional health data civic assembly model, using Indigenous and equity frameworks, that can be sustained and gradually matured over time.
3. A **commitment** to a long-term, multi-tiered Health Data Civic Engagement Strategy: invest in fostering on-going relationships and building public trust, acknowledge wrongdoing and actively work to repair harm, and pursue new civic engagement opportunities.

Only through strategically leveraging the expertise and health system engagement work happening across all sectors will we achieve a more data literate, transparent, and civically engaged health system in Ontario.

¹ See the JMR Report (May 2021), [OHDC Report](#) (October 2022), and [pCHDS EAG Reports](#) (May 2021-May 2022).

Background

“We don’t want the work to end with each project but have a long-term strategy and sustained engagement.”
~Civic Engagement Strategy Working Group Member, 2023

Health data is integral to meeting the needs of patients, families, and caregivers, yet Ontarians only realize a fraction of the potential benefits of health data due to the current practical, financial, and structural barriers in accessing, using, and sharing their health data. Although digital health technology and strong data governance can help reduce barriers and improve access to and quality of health care, nearly 60% of Ontarians lack the necessary digital health literacy to make decisions about their own health and only 35% of them have accessed their health data electronically.² Despite these challenges, patients, families, and caregivers recognize the value of their health data and believe it should be used for broader public good.

As a permanent advisory body to the Minister and Ministry of Health, the Minister’s Patient and Family Advisory Council (MPFAC) provides patient, family, and caregiver perspectives and advice on strategic health policy priorities that have an impact on patient care and patient health care experiences. This includes recommendations on promoting health data literacy and addressing the distinct needs and perspectives of different communities, especially those impacted by technological barriers and health inequities related to the social determinants of health.

In December 2023, the MPFAC affirmed its alignment with the OHDC Report’s vision and recommendations and proposed their participation in this data strategy work through the co-sponsorship of a civic engagement strategy. This strategy would champion greater transparency, digital literacy, and sustained public engagement across Ontario. After the OHDC endorsed a co-sponsorship with the MPFAC on civic engagement work, the MPFAC established a time-limited Civic Engagement Strategy Working Group in February 2023. Over the last three months, the Working Group explored and identified two initiatives—a Transparency Centre and Health Data Civic Assembly Model—to enhance health data literacy and offer opportunities for open dialogue on health data to increase transparency and foster public trust across Ontario. The Working Group collaborated with the ministry to create a Transparency Centre prototype and 5-year roadmap for a provincial-wide Health Data Civic Assembly to help articulate their vision for Ontario’s Civic Engagement Strategy. These materials were presented to the full group of MPFAC members, who provided feedback and voiced their support for the approach.

This Civic Engagement Strategy Advisory Report builds on the OHDC’s vision for Ontario to foster a transparent, inclusive, data-enabled culture, one which engages patients, families, caregivers, providers, planners, and policymakers in a sustained, open dialogue on health data and encourages the active collection, use, protection, and sharing of data for the public good. This vision can only be realized by earning and maintaining public trust, which is essential to achieving a person-centred, learning health system.

² According to the [Canada Health Infoway: Canadian Digital Health Survey \(2022\)](#), almost 90% of Ontarians feel more informed about their health because they can access their health data online, with 85% affirming they can better manage their health with online access to their health data.

Civic Engagement: Giving Voice to People

“The role of the Government is changing. The community is seeking better government leadership through increased **public participation in decision-making**. ... Equally important, it contributes to **building public trust** in government, raising the quality of democracy, and strengthening civic capacity.”

~*Community Engagement Division Directions Statement*, Queensland Government (2001)

There is growing worldwide consensus regarding the need for greater transparency and education around health data use and sharing. The pandemic brought about unprecedented, collaborative cross-sector efforts and legislative changes to enable the collection and sharing of health data, yet the public had little to no opportunity to provide their feedback on these government decisions.

Ontario’s future health system requires the sustained trust, broad support, and collaboration with everyone across the province to achieve a person-centred, learning health system that champions data sharing for the public good. However, people remain uncertain about how the government collects, uses, and shares their health data. While Ontarians generally trust their health care providers and government health departments with their health data, 20% reported being uncomfortable with their health data being shared under any circumstances.³

According to the pan-Canadian Health Data Strategy Expert Advisory Group, most countries implementing health data strategies have identified building and sustaining trust with the public and enhancing health sector and public data literacy as essential to the success of any health data strategy.⁴ The Expert Advisory Group also identifies the need for Canada to create sustained mechanisms for civic engagement to earn and maintain public trust and empower Canadians to improve their health outcomes through their ability to access, manage, and share their health data.

What is Civic Engagement?

Civic engagement refers to public participation in social and political activities to better people’s quality of life by addressing issues of public concern (e.g., climate change, homelessness, health inequity, etc.). It includes a broad spectrum of opportunities—from voting to community governance tables—for the public to actively shape government decision-making.

Meaningful civic engagement is essential to the evolving health data landscape. It is widely recognized as an essential component of good health data governance and foundational to building public trust, civic engagement is vital to the health of democracy, but also the well-being of people since it is generally associated with improved health status and is now even considered a social determinant of health.⁵

In alignment with the pan-Canadian Health Data Strategy Expert Advisory Group and OHDC reports, the Working Group recognizes the need to continuously invest in the literacy and engagement of Ontarians on topics and issues relating to health data. Everyone should be afforded the ability, capacity, and opportunity to help shift Ontario from a data-protectionist culture to one that champions the use and sharing of data for the public good. Before that shift can begin, however, the public and health workforce must be educated and more actively involved.

³ See [Canada Health Infoway: Canadian Perspectives on Digital Health Privacy Survey](#) (2023).

⁴ See the PCHDS EAG’s [Building Canada’s Health Data Foundation](#) (2021).

⁵ See [Examining Civic Engagement Links to Health](#) (2019).

Leading with Trust and Transparency

“Trust is something that’s ongoing and we have to deeply embed it into the work that we’re doing.”

~Civic Engagement Strategy Working Group Member, 2023





To address the growing concerns around the protection, governance, and sharing of data, transparency centres—an important form of civic engagement—continue to gain global traction.⁶

What is a Health Data Transparency Centre?

Health data transparency centres are generally free, one-stop hubs that offer health data literacy resources for the public, and in some cases, open access health data repositories for researchers and policy makers. They sometimes offer engagement opportunities and grants to support on the ground community initiatives. They are usually overseen by government bodies, non-profit organizations, or public advocacy groups.

In June 2020, a Joint Ministers’ Roundtable (JMR), a consultation group of experts chaired by Dr. Jane Philpott, was struck to advise on the design and implementation of the COVID-19 Health Data Platform. In May 2021, the JMR published its report urging Ontario to lead with trust and transparency to engage Ontarians in a dialogue on their data by developing tiered and bi-directional engagement with the public and priority populations⁷ through a web-based Transparency Centre. This one-stop hub would provide Ontarians with culturally appropriate, transparent information and offer opportunities for public engagement on health data.

After conducting a jurisdictional scan of more than a dozen example transparency centres worldwide, the Working Group observed that each centre had four recurring aims. These findings informed the Working Group’s vision for a prospective Transparency Centre in Ontario:

 EDUCATE	<ul style="list-style-type: none">• Health literacy definitions/glossary (e.g., health data) and FAQs (e.g., data access, privacy, and rights)• Health data importance (“Case Studies”; “Patient Stories”; “Power of Health Data”; “Data Saving Lives”)• Health data news articles, websites, journal articles, blogs, campaigns, annual reports, etc.
 ENGAGE	<ul style="list-style-type: none">• Publicize & host call outs for health data civic engagement (e.g., assemblies), events, forums, etc.• Promote dialogue on health data sharing: blog, podcast interview, social media campaigns, etc.• Publish survey and research studies results to increase public trust and transparency
 SUPPORT	<ul style="list-style-type: none">• Create digital health literacy toolkits for patient advocacy groups, educators, & health care professionals• Offer guidance and small grants for outreach programs and community-led initiatives• Liaise with government bodies to advocate on behalf of Ontarians
 REPORT	<ul style="list-style-type: none">• Showcase accessible materials (e.g., infographics) that highlight how data is collected, stored, & shared• Provide transparent inventory of datasets, where they are stored, and how they are used• Ensure public oversight and governance decisions on how data is collected, stored, and shared

⁶ See [Understanding Patient Data](#), [Data Saves Lives](#), [Citizens Information \(Ireland\)](#), etc.

⁷ According to the JMR Report (May 2021), “priority populations” are defined as at-risk populations for whom public health interventions may be reasonably considered to have a substantial impact: BIPOC and ethno-racial communities that experience racism; immigrants, migrants, and refugees; marginalized genders and sexual orientations; francophone and linguistic communities; people with high-risk clinical needs; people with physical and/or mental health disabilities; religious/faith communities; homeless people; people living on a low income and/or receiving social assistance; people suffering from substance use; and people living in rural/remote or inner urban areas.

Strengthening Civic Capacity

“If you want to go far, go further. One person cannot speak as a monolith for a community. We link democratic processes to the majority, but if you’re aiming for equity, you may not have everyone represented. We need to consider models that explore how people can shift, disrupt, and topple paradigms and recognize those who have been historically underrepresented in these spaces.”

~Civic Engagement Strategy Working Group Member, 2023





Civic assemblies⁸—a powerful form of civic engagement—offer people the chance to effect real change. They are also critical in the face of waning public trust in democracy, as voting is no longer considered enough to ensure people’s voices are reflected in government decisions.

What is a Health Data Civic Assembly?

Also known as citizen juries, panels, and/or summits, civic assemblies involve diverse groups of people learning and deliberating on specific policy issues and offering advice on immediate and long-term solutions. Health data civic assemblies focus specifically on health data related topics. In addition to helping the government understand what an informed public wants and needs, civic assemblies enhance people’s trust in democracy and secure their belief in their own ability to effect change.

It is essential for public interests to be at the centre of health data strategies and policies. According to the pan-Canadian Health Data Strategy Expert Advisory Group, a world-class health system is person-centric. To foster public trust, the Expert Advisory Group recommends that an on-going, pan-Canadian public assembly—in parallel with regional or sub-regional assemblies—should be established to advise governments on the responsible governance of health data for public benefit. The Expert Advisory Group recommends that the assembly be chaired by a member of the public, designed to include diverse perspectives and experiences (including equity-deserving groups), and structured based on fixed-term membership.

The Civic Engagement Strategy Working Group conducted a jurisdictional scan of more than 100 civic assemblies on health data-related issues worldwide and observed that each assembly had four common roles. These findings informed the Working Group’s vision for Ontario’s Health Data Civic Assembly:

Sponsorship 	<ul style="list-style-type: none"> Organization and/or group of people (e.g., academic researchers) who provide the funding, secretariat support, and policy-making expertise
Oversight Board / Panel 	<ul style="list-style-type: none"> Small group with range of expertise (academia, patient advocacy, citizen engagement, digital health, research, etc.) appointed to consult on the assembly design, review expert witness materials, and report findings to sponsoring group
Expert Witnesses 	<ul style="list-style-type: none"> Field experts who present neutral overview of assembly topic
Participants (“Jurors”/ “Members”) 	<ul style="list-style-type: none"> ~12-100 people randomly recruited based on sociodemographic diversity

⁸ Civic assemblies “are built on the belief that given enough knowledge, resources, and time, groups of every day citizens can create powerful solutions to today’s biggest challenges” (Centre for New Democratic Processes, 2022).

Data for Good: Ontario’s Transparency Centre

“The goal of this work is to move away from data as product to data as *stories*.”

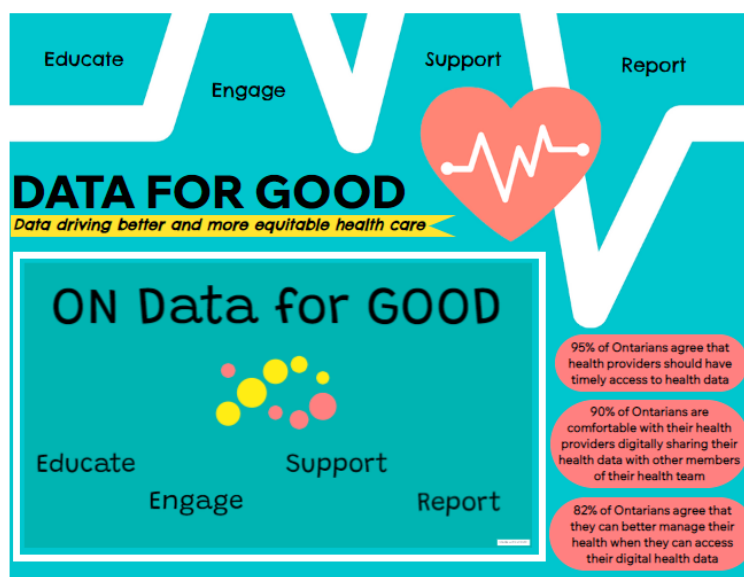
~Civic Engagement Strategy Working Group Member, 2023

The future health system requires the sustained *trust* of Ontarians: seamless data sharing for the public good cannot be achieved without *transparency*.

As a result of the harms of past and current misuses and misappropriations of Black, First Nations, Inuit, and Métis (FNIM), racialized, and vulnerable peoples’ data, Ontario must acknowledge and address data harms, barriers, and inequities and actively work to rebuild trust through transparent reporting and dialogue on how health data is collected, protected, used, and shared.

Echoing the JMR Report, the Working Group urges Ontario to lead with trust and transparency. To realize the OHDC’s vision for a more empowered, engaged, and educated data and digitally literate public, the Working Group recommends the launch of a public-facing, welcoming, accessible website that fosters open dialogue on health data. This website would provide an opportunity to speak candidly about health data historical harms⁹ and barriers and showcase the power of data to change lives and empower people to make their health data work for them.

Figure 1: Transparency Centre Prototype¹⁰



Mission: To educate, engage, support, and report to Ontarians on the collection, use, protection, and sharing of health data for the purpose of strengthening Ontario’s health system and ensuring a healthier Ontario.

Purpose: This website would equip the public as well as health providers and planners to become more informed about their health and empower them to become health data for good advocates.

Through this website, the people across Ontario would:

⁹ In line with the OHDC Report, the Working Group acknowledges that First Nations, Inuit, and Métis peoples have not always been respected and have been in fact harmed by appropriation, misrepresentation, and exploitation of their data for uses which have not been in their best interests. As a result, trust has been lost. This trust can only be rebuilt through open dialogue and relationships founded on mutual respect and understanding.

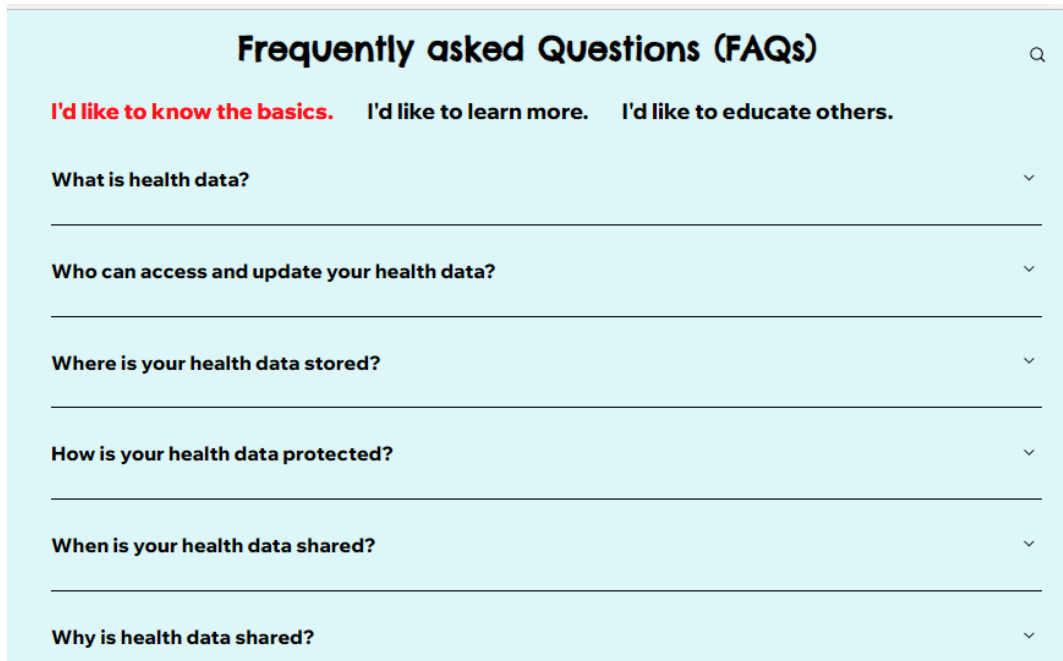
¹⁰ Inspiration for this prototype came from existing transparency centres (i.e., [Transform Health](#), [Understanding Patient Data](#), [My Health Data Path](#), etc.). The ministry would require a professional website designer and marketing firm moving forward. Currently, the Ontario government owns a website domain until March 15, 2024.

- Understand the basics about health data, including how it is protected, used, and shared
- Recognize the benefits of sharing health data for good through real world examples
- Learn how their health data can work for them to improve their care experiences
- Raise awareness and promote dialogue on and engagement with health data issues and
- Participate in government decision-making about health data collection, use, and sharing.

The Working Group recommends that Ontario’s Transparency Centre should be:

- Engaging, interactive, and public-friendly (e.g., multi-media, multi-lingual, etc.)
- Transparent about health data historical harms and barriers to aid towards reconciliation
- Educational, accessible, and equitable in terms of its functionality and literacy resources
- Layered in terms of content to encourage the public to learn at their own pace.

Figure 2: Example of Layered Content to “meet people where they are at”



The Working Group also recommends gradually maturing the centre by incorporating:

- Health data literacy toolkits designed for different audiences (public, educators, health providers, health system planners, etc.)
- Health data support resources, including opportunities for community grants
- Transparent inventory of health datasets with explanations of their use, categorized by people’s interests, and offering opportunities for gaps in the data to be shared.

Before this initiative moves forward, the Working Group recommends socializing this prototype and the context for this work with key health system stakeholders. The next phase of this work would potentially be modeled after the OHDC-sponsored Dialogue on Data consultations.¹¹

¹¹ See the [OHDC Report](#) (2022).

Ontario's Health Data Civic Assembly

"I think that implementing a Health Data Civic Assembly will not only inspire more public trust in the healthcare system but will help set Ontario apart as a leader when it comes to integrating the patient and caregiver voices into healthcare policy."

~MPFAC Member, 2023

The future health system requires broad *support* from and *collaboration* with Ontarians: a person-centred, learning health system cannot be achieved without *public engagement*.

Health touches the lives of people very personally. Deliberative democracy, an inclusive vehicle for public engagement, is therefore necessary to democratizing and deciding health policy for the public good. As the definition of health data continues to expand and new health data use cases emerge, Ontario must provide the public a space for open dialogue and foster a culture of informed engagement and decision-making.

Although the Ministry of Health currently offers various channels¹² for the public to provide their input and feedback on health data priorities and concerns for government consideration, Ontario lacks a permanent mechanism that allows for a sustained, bi-directional approach to health data civic engagement that connects diverse groups of Ontarians across the province.

Echoing the pan-Canadian Health Data Strategy Expert Advisory Group, the Working Group urges Ontario to build civic capacity through the establishment of a public engagement infrastructure for broader, meaningful, and ongoing dialogue on health data decision-making. To realize the OHDC's vision for everyone across Ontario with broad ranges of expertise and lived experiences to be actively engaged in shaping Ontario's health system, the Working Group recommends implementing a provincial-wide Health Data Civic Assembly.

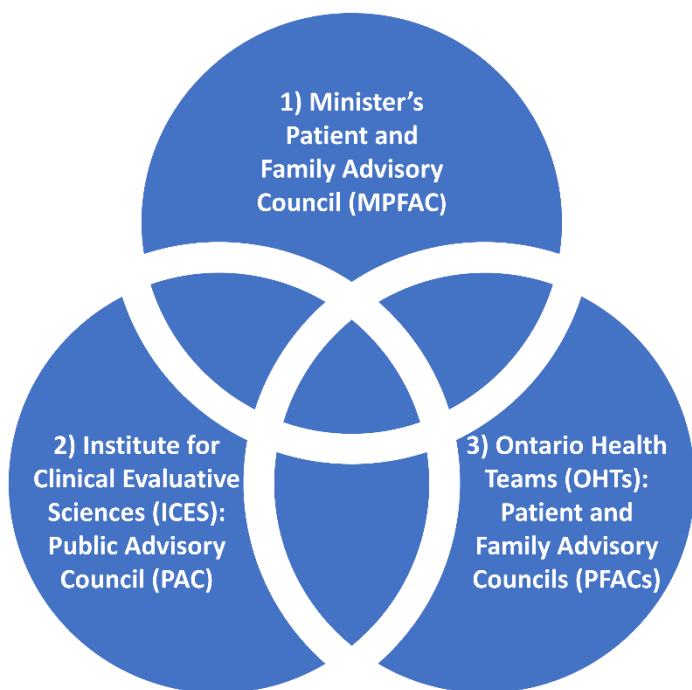
This initiative would be first piloted and spearheaded by an established panel with public/patient engagement expertise to conduct research (e.g., explore distinctions-based,¹³ trauma-informed, bi-directional, and intersectional frameworks, etc.), test logistics (e.g., run an "in-house" assembly, which would involve consulting with key expert stakeholders), and grow the model to maturity.

To create a successful Health Data Civic Assembly, Ontario must first leverage and coordinate health data civic engagement assets already in place (see Figure 2). Ontario must catalyze broader discussions on health data and collaborate on building a sustained public engagement community of practice across Ontario that ensures equitable representation.

¹² For example, the Ontario Health Data Council's *Dialogue on Data*, the MPFAC's Digital Health Subcommittee, [ICES Public Advisory Council \(PAC\)](#), the Ministry-sponsored [McMaster Health Forum Citizen Panel](#) on health data, etc.

¹³ Distinctions-based partnerships recognizes that First Nations, Inuit, and Métis (FNIM) peoples are not one unified group, but rather represent many unique peoples with distinct cultural heritages, languages, values, needs, and rights. FNIM peoples have different needs, preferences, and strategies regarding the governance of their health data.

Figure 3: Ontario's Health Data Civic Engagement Assets








- ✓ Advises the Minister of Health
- ✓ Co-designs health care policy
- ✓ Advances partnerships & engagements with patients, families, & caregivers

- ✓ Ontario's "Best Kept Secret"
- ✓ Provides public perspective on health data research
- ✓ Shapes ICES' approach to improving Ontario's health care through health data research

- ✓ Engages and empowers public to shape their local health care
- ✓ Advises on and in some cases co-designs health programming
- ✓ Advocates for better health care

The Civic Engagement Strategy Working Group recommends exploring the below 5-year roadmap for maturing Ontario's Health Data Civic Assembly.

Figure 4: Ontario's Health Data Civic Assembly - Example Roadmap to Maturity

Health Data Civic Assembly 1.0 (Year 1)	Health Data Civic Assembly 2.0 (Years 2-4)	Health Data Civic Assembly 3.0 (Year 5+)
<p>MPFAC Health Data Civic Assembly Subcommittee</p> <p>MPFAC Subcommittee are the Assembly members</p>  <ul style="list-style-type: none"> ✓ Pilot and test model 'in-house' ✓ Stakeholder consultations ✓ Report on lessons learned 	<p>OHDC's Health Data Civic Assembly (HDCA)</p> <p>MPFAC Subcommittee are the HDCA Oversight Panel</p> <p>OHDC sponsors  HDCA Oversight Panel </p>  <ul style="list-style-type: none"> ✓ Topics & experts proposed by OHDC ✓ Ministry-run health data assemblies ✓ Leverage PFAC engagement channels 	<p>Ontario's Health Data Civic Assembly (OHDCA)</p> <p>Permanent, publicly-run organization that serves as a formal health data advisory body to the Ministry</p>  <ul style="list-style-type: none"> ✓ Advisory body to Ministry of Health ✓ Oversight board: permanent Council ✓ Assembly: staggered membership

This roadmap provides an example sustained approach for building a Health Data Civic Assembly in Ontario to provide advice to the Ministry on health data policymaking. **Any decision to move forward on this initiative would be dependent on capacity, resources, and funding and therefore subject to change.**

Health Data Civic Assembly 1.0: MPFAC Health Data Civic Assembly Subcommittee¹⁴



As the current patient and family-led health policy advisory body to the Minister of Health, the Minister’s Patient and Family Advisory Council—pending capacity, resources, and funding—is well-positioned and supported to serve as Ontario’s first Health Data Civic Assembly to pilot and mature Ontario’s Health Data Civic Assembly model. The MPFAC’s current role as an advisory body to the Minister and Ministry of Health includes:

- Providing advice to the Minister on key health policy priorities and patient engagement activities
- Serving as the central body to help identify issues relating to care or health care experiences of patients and families across the health care system and
- Identifying and advising on opportunities to incorporate the perspectives of patients and their families in the policy development process.

Future opportunities are being explored for the MPFAC and the ministry to collaborate on this work. This could include an ongoing civic engagement subcommittee of the MPFAC.

To achieve a truly inclusive, trauma-informed, intersectional, and bi-directional Health Data Civic Assembly in Ontario, the prospective subcommittee would engage key stakeholders on the assembly question: “What does an inclusive and representative health data civic assembly look like?” This list of stakeholders would be generated in partnership with the OHDC (see Figure 4), should a subcommittee be struck. The consultations from this pilot “in-house” Health Data Civic Assembly will inform the design of the second phase of the above roadmap.

Figure 4: Health Data Civic Assembly - Example Key Stakeholders



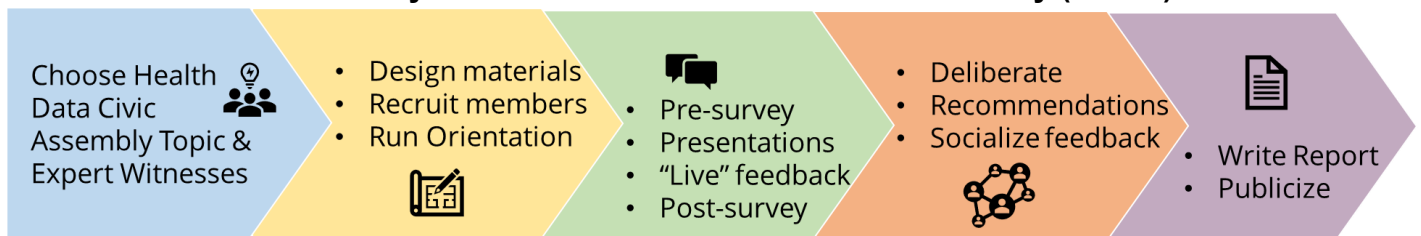
¹⁴ The Civic Engagement Strategy Working Group members expressed their interest in participating in the next phase of the work and guiding its roll out and development. They propose leveraging the diverse talent and skillset of the larger MPFAC for additional capacity support. They are however mindful of capacity as there are two current MPFAC subcommittees. This proposed subcommittee could be structured after current subcommittees (e.g., meeting frequency, honourarium, supported by ministry secretariats, etc.).

In parallel with these consultations, the subcommittee would aim to establish distinctions-based partnerships with First Nations, Inuit, and Métis peoples due to their unique health data governance needs, preferences, and strategies. These engagements should be undertaken via their representative organizations (see Figure 5) to acknowledge and respect First Nations, Inuit, and Métis peoples’ rights to self-determination, including self-governance and data sovereignty.

Figure 5: Health Data Civic Assembly – Example Organizations Representing First Nations, Inuit, and Métis Peoples



Health Data Civic Assembly 2.0: OHDC’s Health Data Civic Assembly (HDCA)



Inspired by the Institute for Clinical Evaluative Sciences (ICES) Public Advisory Council (PAC) model¹⁵ and informed by the above consultations, the proposed OHDC-sponsored Health Data Civic Assembly would involve the recruitment of a diverse group of people¹⁶ to serve on each assembly to deliberate on health data topics and advise on recommendations. The OHDC would propose health data topics and suggest expert witnesses and the MPFAC Subcommittee would provide oversight (e.g., consult on the assembly design and review chosen health data topics and expert witness materials). Each assembly would leverage existing engagement channels (e.g., Ministry virtual pool of PFAC advisors, ICES’ Public Advisory Council, and OHT PFACs) and offer “live” feedback options for participants to provide further input on the recommendations. The MPFAC subcommittee would then submit their report findings to the OHDC to be tabled with the Minister of Health. These assembly reports would then be made available to the public.

Health Data Civic Assembly 3.0: Ontario’s Health Data Civic Assembly (OHDCA)

The Working Group’s vision for the Ontario Health Data Civic Assembly includes a permanent, publicly run organization that would serve as an advisory body and formal accountability measure of the Ministry of Health. Inspired by existing permanent civic assemblies,¹⁷ the OHDCA would:

- Host health data public assemblies and survey the public on health data issues
- Advise on and shape health data policy and
- Track government progress and hold government accountable on health data policy.

To ensure continuity, the MPFAC Chair could serve as an ex-officio member of this advisory body.

¹⁵ The Working Group incorporated [ICES’ Public Advisory Council \(PAC\)](#) framework into its maturity roadmap.

¹⁶ Public call outs for these assemblies would be required. In alignment with PAC’s model, applicants would be selected to ensure each assembly’s demographic diversity.

¹⁷ See [Belgium’s “Citizens’ Dialogue”](#) and [Ireland’s “The Citizens’ Assembly”](#).

Proposed Next Steps

The Working Group recommends the following next steps:



Socialize the Transparency Centre prototype and supplementary context materials (e.g., walk-through video) with key health system stakeholders¹⁸ and consider using target/focus groups (e.g., youth, seniors, etc.) to review/test the prototype for additional feedback.



Strike a Health Data Civic Assembly subcommittee to oversee key stakeholder consultations on the question, “What does an inclusive and representative health data civic assembly look like?” and establish, in parallel, distinctions-based relationships with First Nations, Inuit, and Métis’ peoples and equity groups by inviting them to the table for these discussions.



Explore new opportunities for civic engagement (e.g., Community Governance Tables) in partnership with other ministry and publicly led projects (e.g., sociodemographic data collection engagement with equity-deserving communities, people of colour, people with disabilities, newcomers to Canada, etc.) and ensure that this important civic engagement work carries forward.

¹⁸ For example, OHT PFACs, 811 Connect, National Caregiver populations, larger hospital PFACs, RISE Community of Practice, community health care workers, mental health workers, community health practice leaders, etc.

Appendix A: Patient, Family, and Caregiver Declaration of Values for Ontario

ACCOUNTABILITY

- ◆ We expect open and seamless communication about our care.
- ◆ We expect that everyone on our care team will be accountable and supported to carry out their roles and responsibilities effectively.
- ◆ We expect a health care culture that demonstrates that it values the experiences of patients, families and caregivers and incorporates this knowledge into policy, planning and decision making.
- ◆ We expect that patient, family and caregiver experiences and outcomes will drive the accountability of the health care system and those who deliver services, programs and care within it.
- ◆ We expect that health care providers will act with integrity by acknowledging their abilities, biases, and limitations.
- ◆ We expect health care providers to comply with their professional responsibilities and to deliver safe care.

EMPATHY & COMPASSION

- ◆ We expect that health care providers will act with empathy, kindness, and compassion.
- ◆ We expect individualized care plans that acknowledge our unique physical, mental, emotional, cultural, and spiritual needs.
- ◆ We expect that we will be treated in a manner free from stigma, assumptions, bias, and blame.
- ◆ We expect health care system providers and leaders will understand that their words, actions, and decisions strongly impact the lives of patients, families and caregivers.

EQUITY & ENGAGEMENT

- ◆ We expect equal and fair access to the health care system and services for all regardless of ability, race, ethnicity, language, background, place of origin, gender identity, sexual orientation, age, religion, socioeconomic status, education, or location within Ontario. We further expect equal and fair access to health care services for people with disabilities and those who have historically faced stigmatization.
- ◆ We expect that we will have opportunities to be included in health care policy development and program design at local, regional, and provincial levels of the health care system.
- ◆ We expect an awareness of and efforts to eliminate systemic racism and discrimination, including identification and removal of systemic barriers that contribute to inequitable health care outcomes (with particular attention to those most adversely impacted by systemic racism).

RESPECT & DIGNITY

- ◆ We expect that our individual identity, beliefs, history, culture, and ability will be respected in our care.
- ◆ We expect health care providers will introduce themselves and identify their role in our care.
- ◆ We expect that we will be recognized as part of the care team, to be fully informed about our condition, and have the right to make choices in our care.
- ◆ We expect that patients, families and caregivers be treated with respect and considered valuable partners on the care team.
- ◆ We expect that our personal health information belongs to us, and that it remain private, respected, and protected.

TRANSPARENCY

- ◆ We expect that we will be proactively and meaningfully involved in conversations about our care, considering options for our care, and decisions about our care.
- ◆ We expect that our health records will be accurate, complete, available, and accessible across the provincial health system at our request.
- ◆ We expect a transparent, clear, and fair process to express a complaint, concern, or compliment about our care that does not impact the quality of the care we receive.

Updated: July 2021

Note: The purpose of this Patient, Family and Caregiver Declaration of Values, drafted by the Minister's Patient and Family Advisory Council in consultation with Ontarians, is to articulate patient, family and caregiver expectations of Ontario's health care system. The Declaration is intended to serve as a compass for the individuals and organizations who are involved in health care and reflects a summary of the principles and values that patients, families and caregivers say are important to them. The Declaration is not intended to establish, alter or affect any legal rights or obligations, and must be interpreted in a manner that is consistent with applicable law.