

Persons with Lived Experience Focused Dialogue

Toronto Marriott City Centre Hotel, Toronto, ON Sept. 7, 2023



Introduction

On Sept. 7, 2023, the CMA held its first in-person focused dialogue in Toronto to kick off a national conversation on public and private health care in Canada. This was the first of several sessions that the CMA is hosting over the coming months to get comprehensive feedback on a complex, critical issue facing our health system (see Appendix A for additional context).

The key objectives of these dialogues are to:

- 1. Surface and explore the values and tensions that underpin the public-private care debate
- 2. Learn from experiences in the current system, both positive and negative
- 3. Seek perspectives and ideas to inform the CMA's policy recommendations on public and private care

Ultimately, the CMA's primary goal with these focused dialogues is to lead informed, constructive discussions to provide insight on how the Canadian health system should transform to ensure patients receive equitable, timely access to care and providers thrive in healthy, safe work environments.

Profile of participants

The CMA reached out to a broad range of persons with lived experience (PWLEs) to solicit their interest in this focused dialogue. This outreach was done in two waves:

- 1. We conducted targeted outreach with the CMA's <u>Patient Voice</u> group and other known patient advocates in the greater Toronto area.
- 2. We connected with several national patient partner organizations and asked them to nominate patient representatives for the session. Some examples of organizations we reached out to are the Centre of Excellence on Partnership with Patients and the Public, Healthcare Excellence Canada, the Canadian Cancer Society, March of Dimes, the Canadian Women's Heart Health Alliance, the National Association of Federal Retirees and the Alzheimer Society of Canada.

Twenty-nine PWLEs participated in the Toronto dialogue. Below is a high-level snapshot of those in attendance:

- Geographic location: There were participants who resided in both rural and urban settings.
- Social determinants of health: The group had a diverse range of lived experiences and circumstances that shape their daily lives and health and well-being. Among the participants, variations in income, education, gender, ethnicity, family structures and community resource access were represented.
- Lived experiences with health care: There were numerous participants who identified as having lived experience in acute and/or chronic care, as well as participants who identified as living with a disability.
- Patient/caregiver mix: Some participants identified as patients and others as caregivers.
- Patient advocacy: Several participants identified as being patient advisors and/or sitting as patient representatives on a board.

What we heard

The three-hour session was dynamic, with lively conversations in the plenary and small groups. Throughout the dialogue, participants reflected on the role of public and private health care delivery and funding in Canada and provided insight on what *they* think should be guiding principles to shape the health system they want moving forward.

Key discussion topics

Patient-partnered and -centred care

Throughout the dialogue, participants emphasized that we need a health system that is more patient partnered and centred and that a fundamental aspect of that is ensuring patients' rights are upheld and care is focused on patient safety. One key recommendation that was proposed was to create more patient advocate positions within the health system. It was noted that having access to patient advocates is particularly important for patients who are not able to speak up for themselves.

Participants highlighted that physicians should not have to bear the sole responsibility for advocating for patients, especially given how overextended they are, and that the creation of more patient advocate positions could help fill this gap. Several participants also thought that patients should be more involved in health system design, planning, monitoring, evaluation and reform to foster patient safety and "patient-focused solutions."

Equity

The belief that everyone in Canada should have equitable access to care, regardless of race, gender, sex, sexual orientation, age, disability, religion, language, ability to pay or other factors, was heard loud and clear throughout the session. Many participants noted that a holistic perspective should be taken to effectively advance health equity, which would include sufficiently recognizing and accounting for the social determinants of health.

Timely access

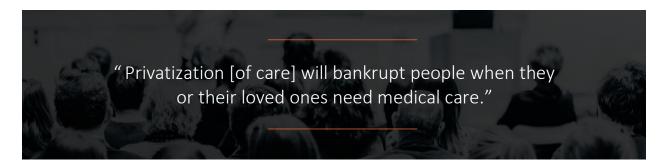
There was a strong consensus that everyone in Canada deserves timely access to care. However, many participants had questions about what is meant by timely access. They underscored the need for it to be more clearly defined and for a consistent definition to be used across the country that is grounded in evidence and global standards. Many participants also emphasized that promoting timely access should not jeopardize equity and that people in Canada should have "[access to] quality care at the right time in the right place that is affordable."

Choice

The concept of choice came up frequently in the discussion. Some participants were not opposed to the idea of having alternative options to access care, including through the private financing of health care, "as long as access is not compromised" and physicians practising in the private system "give back to the public [system]." These participants felt that "those who have the means will want to pay [to access care]," so the option should be provided.

"Those who have the means will want to pay [to access care]"

On the other hand, some participants felt that exploring alternative options to access care often means "to pay to access," which will create a health system that is inaccessible to those who cannot afford it. Several participants expressed significant concerns that some patients will be put "at the bottom of the waiting list as others get ahead" and treated unfairly "for medical procedures." There were many fears that exploring and adopting models of privately financed health care will deeply entrench inequities, where "privatization [of care] will bankrupt people when they or their loved ones need medical care." Numerous participants stated that they would instead like to see more investment and improvement in a "completely publicly funded and delivered national health care system."



Another aspect of the discussion around "choice" was centred on patients' choice in health providers, where some participants felt that patients should have a say in who provides their care, particularly if their rights as patients are not being upheld. Other participants highlighted how "choice isn't possible now — no one can access primary care in some areas [of the country]," rendering the discussion on patients' choice "meaningless."



Enhance community-based primary care

Several participants felt that supporting and scaling up publicly funded community-based primary care is a fundamental way to improve access to care for everyone in Canada. Many hoped for a health system that had "enough family physicians to direct the care of all Canadians." Some participants also suggested that we should optimize health human resources, which would include "increasing [the] utilization of nurse practitioners in nurse practitioner-led clinics." Ultimately, participants largely supported team-based care models where various providers, such as medical scribes and physician assistants, are effectively working together to support "the continuity of care and [patient] navigation of the [health] system."

In particular, participants advocated for increased long-term investments in community-based, preventive care. Participants noted that "maybe spending should be upstream, [focused on the] social determinants of health, prevention, etcetera" to build healthier communities as "the science shows if we can be more proactive, we can avoid a lot of diseases." Several participants recommended that the Canadian health system take a more proactive approach to health care by supporting upstream investments in preventive care, which would build healthier communities and reduce downstream demand on overstretched emergency departments and other acute care services.

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Care for older adults

Many participants had significant concerns around the growing lack of care for older adults in our country. Participants described how "long-term care for seniors is failing" and said that "we should be ashamed" at what happened with long-term care in Ontario (referring to the fact that long-term care residents have been disproportionately impacted by COVID-19 infections and death). It was emphasized that our health system needs to urgently "fix" home care and long-term care to ensure older adults in Canada are fully cared for. Several participants were fearful that "seniors and the aging population will not have access to health care in this decade."



Leverage technology

Many participants raised the importance of leveraging technology to support patient empowerment and access to care in Canada. The benefits of virtual care were frequently mentioned, and it was suggested that health systems should continue to improve virtual services and support the adoption of more digital technologies in health care. Several participants noted that they want to keep and expand virtual care, particularly in remote communities as it would allow physicians to more continuously and effectively care for patients who live in these areas. Participants also mentioned opportunities to further utilize artificial intelligence to support the delivery of health care, including remote patient monitoring for chronic illnesses.

In addition to the opportunities, some participants spoke about the challenges that the further adoption of artificial intelligence in health care could pose. They suggested that Canada should establish strong digital data governance mechanisms to effectively address the "privacy, safety and ethical concerns" that could arise with the increasing use of technology in health care.

Exploration, evaluation and updating of the definition of "medically necessary"

Throughout the dialogue, one fundamental question kept coming up: "What is medically necessary care and who should define it?" Currently, the Canada Health Act defines medically necessary services as hospital services, physician services and surgical dental services that require a hospital setting. For the most part, participants felt the need to further expand the definition of "necessary" medical services in Canada, so health services such as dental care, prescription drugs, eye care, physiotherapy, mental health care, community rehabilitation services, home care and long-term care would be publicly financed.

One participant provided an example of her child having a locked jaw and a tooth growing in the wrong direction; she said that since she cannot afford to pay for this necessary dental care, her daughter's oral health issue will be left untreated. Most participants strongly felt that situations like this should not happen, and patients should be able to receive all the care that they need free of cost, which is why they suggested that a more holistic definition of "medically necessary" be developed with the input of patients and providers. It was also recommended that the definition be consistently adopted across the country so there are clear standards and a mutual understanding of what is meant by "medically necessary" services.

Accountability

There was a strong consensus that external oversight is needed to ensure that decisions are made in patients' best interests and governments are held accountable for public money spent on health care. Participants emphasized that the public should know how much money is allocated to health care and how the allocated dollars are spent. Additionally, most, if not all, participants felt that the health system, regardless of how it is funded and delivered, must be held accountable as it relates to tracking and improving patient outcomes.

The lack of oversight and regulation of privately delivered and financed long-term care homes in Ontario was frequently cited as an example of why we need strong accountability mechanisms to ensure patients are not receiving sub-standard or harmful care. Many participants noted that there should be clear standards across the country to help promote accountability and measure progress. It was specifically recommended that an arm's-length oversight body could offer this type of accountability and that patient representatives should be included in this body. A few participants also emphasized the importance of community-based oversight, which would enable patients, families and providers to provide input and ensure that their feedback would be meaningfully heard and acted upon.

Moving forward: How might we shift?

Despite the fears that were conveyed throughout the discussion, a clear sense of hope also came through. Participants offered several ideas on how to improve health care access in Canada and foster a healthy and safe work environment for providers.

Below are some of the key suggestions, which link to many of the discussion topics previously outlined:

- Embed a patient-partnered and -centred approach: Respect and uphold the rights and safety of patients, and meaningfully include patients and patient advocates in health system design, planning, management, evaluation and reform.
- Recognize and account for the social determinants of health: Health systems should better identify and address the social determinants of health to promote a more holistic approach to patient care and eliminate health disparities more effectively.
- Fund and expand community-based primary care models: Participants strongly felt that public funding needs to increase for preventive care (versus acute care), which they suggested could be done by sufficiently investing in community-based primary care models.
- Streamline health systems through various mechanisms, including the following:
 - Have clear standards of care that are well communicated, understood and consistently implemented across the country so that patients' rights are fully respected and upheld, and both patients and providers have a shared understanding of these standards.
 - Leverage technology to promote innovations and efficiencies within the health system. Key recommendations included further expansion of virtual care and unification of the electronic medical record (EMR) system to support more integrated and continuous care for patients and reduce the administrative burden on physicians.
 - o Implement centralized waitlists and referral systems across the country.
 - Adopt a national licensing system for physicians and reduce barriers for foreign-trained health professionals to work as health care providers in Canada.
- *Increase accountability:* An independent oversight body could be created to track health care financing and delivery, as well as patient and population health outcomes.

What's next?

The session in Toronto was the first of a series of focused dialogues. There will be future opportunities for both the public and physicians to engage in this important discussion, including the following:

- The CMA has partnered with *The Globe and Mail* to sponsor a <u>series of townhalls</u> across the country.
- The public and physicians can keep the conversation going by joining <u>CMA Community</u>, our new online community space.
- Go to the <u>CMA's public-private</u> webpage and fill in your contact information to stay abreast of key updates.

The CMA greatly appreciates the time participants took to attend the Toronto in-person focused dialogue. The insightful feedback and perspectives provided will continue to be analyzed and will inform the CMA's future policy and advocacy in this area.

APPENDIX A: Context of the CMA's consultations on public and private care in Canada

This series of discussions is timely as the country is currently at a critical juncture, where many in Canada are feeling the dire impacts of a crumbling health system. A recent <u>Angus Reid Institute survey</u>, released in August 2023, outlined that only 4% of Ontarian respondents felt that the current health care system is working well, and 61% reported either "some challenges" or "chronic difficulties" accessing care. Additionally, almost 10% said they had no access to a primary care provider at all.

Coupled with a lack of access to care, we know that privately funded care already exists in Canada, where it is estimated to account for 28% of health care spending. It is also becoming evident that with the increasing access issue in our country, more people are exploring private health care options to try to receive care in a timely manner. This reality demonstrates that we need more clarity, research and evidence to gain further insight into what models of health care financing and delivery will result in the best patient outcomes.

Owing to the complex nature of this issue, a context-setting presentation was provided to participants at the beginning of the dialogue. In Canada, like many other countries, there is an intricate mix of public and private health care delivery and funding. The table below provides some highlights of how the health system operates in Canada.

Health services	Funding (How services are paid for)	Delivery (How services are organized, managed and provided)
Hospitals Physicians Diagnostics	Public taxation	Mixed delivery, but largely private For example: • Hospitals are often incorporated private foundations. • Family physicians often bill provinces and territories as independent, private contractors.
Public health Community health centres	Public taxation	Typically public For example: municipally run community resource centres, sexual health clinics, immunization services, harm reduction services
Prescription drugs Home care Long-term care (LTC) Mental health care Dental care Vision care Outpatient physiotherapy Complementary medicine (e.g., massage therapy)	Mixed funding Public taxation Private insurance Out-of-pocket payments (private)	 Mixed delivery For example: In Ontario 16% of LTC homes are publicly owned and 84% are privately owned.² BC, Saskatchewan and the territories largely publicly deliver home care, whereas all other provinces typically contract private companies to deliver home care services. Most dentists and optometrists work as independent, private contractors or employees for a private employer.

¹ Canadian Institute for Health Information. Who is paying for these services? Accessed Sept. 17, 2023.

² Canadian Institute for Health Information. Long-term care homes in Canada: How many and who owns them? Accessed Sept. 17, 2023.

Another important consideration when examining the role of private and public care is the fact that when health services are privately delivered, they can be run by a **not-for-profit** or **for-profit** agency. For example, in Ontario, out of the 84% of LTC homes that are privately owned, 57% are owned by private for-profit organizations and 27% are owned by private not-for-profit organizations.³

In this context, the CMA believes it's time for open, honest conversations with patients, providers and the public to create a health system that meets the needs of everyone in Canada. "This conversation is not easy," notes CMA President Dr. Kathleen Ross, but private care "is already happening and [governments are] making decisions around increasing [it]... we must have the courage to have these tough conversations."

³ Canadian Institute for Health Information. Long-term care homes in Canada: How many and who owns them? Accessed Sept. 17, 2023.

APPENDIX B: Focused dialogue agenda



CONSULTATIONS ON PUBLIC AND PRIVATE CARE IN CANADA

CMA PUBLIC-PRIVATE FOCUSED DIALOGUE (PERSONS WITH LIVED EXPERIENCE)

Thurs., Sept. 7, 2023 — 2:30–5:30 pm ET Toronto Marriott City Centre, Blue Jays Room

Objectives

- Surface and explore the values and tensions that underpin the public-private care debate.
- Learn from your experiences in the current system, both positive and negative.
- Seek your perspectives and ideas to inform our policy recommendations on public and private care.

AGENDA AT A GLANCE

TIME (ET)	ACTIVITY
2:30–3 pm	Opening and warm-up
3–3:40 pm	Context-setting presentation Plenary Q&A and dialogue
3:40–3:55 pm	Health break
3:55–5 pm	Table discussions: guiding principles for public-private care
5–5:20 pm	Report back and plenary dialogue
5:20–5:30 pm	Recap, next steps and closing
5:30–6 pm	Dinner buffet



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