

2023 Ontario Budget Submission - Participating Patient Groups



We are pleased to provide our collective recommendations in the area of healthcare as part of the Ontario Pre-Budget Submission process.

General Comments

We are pleased to see the provinces, territories, and Federal Government coming to the table to address the critical issues with our healthcare system. While the proposed \$196B ten-year deal will help address many of the current issues and hurdles, we concur with Premier Ford that there may be more investment required. To that end, it will be critically important to ensure that all upcoming decisions regarding resource allocation and priority areas in Ontario be inclusive in terms of seeking expert advice. It will be important to ensure that there is sufficient funding to tackle the immediate pressures on the system, as well as putting time and energy into a long-term strategy that will modernize our system.

We commend the Ontario government for being an active leader in the discussions around CHT to date. We are pleased to see an increase in the CHT floor from 3% to 5% for the next five years.

Finally, tracking the investments into healthcare and being transparent about the results, whether positive, negative, or both, will be foundational to the success of modernizing Ontario's healthcare system, and will help ensure the public is (and remains) onside. The intent of doing so is not to be critical of under-performers but rather to share promising and best practices in order to adapt them to different settings and jurisdictions to continually improve across Ontario's and Canada's health systems.

GENERAL RECOMMENDATIONS

General Recommendation 1: Allocate all CHT funding directly to healthcare (rather than to General Revenue or other projects), without delay, and use the funding to tackle the priorities identified by the Federal Government recognizing that delays have a more dire impact on certain serious illnesses.

General Recommendation 2: Now that we understand the value of the offer on the table from the Federal Government, we recommend that Ontario bring together experts in each of the priority areas, as well as experts in social determinants of health, and FNIM representatives, to review Ontario's proposed overall Action Plan to ensure we have the potential to achieve our shared objectives and that we have focused on the most innovative, effective and resilient solutions.

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We propose that the Expert Advisors help determine how to allocate Ontario's portion of the \$2B announced in the Plan to address immediate pressures on the healthcare system, including backlogs, as well as longer-term planning with regard to the \$25B announced toward the shared priorities.

Experts can help Ontario be ready to pivot as necessary, redesigning the planned approach, and reallocating the planned investments as required. Experts can advise on how to use the funding in the most efficient and effective ways possible. In addition, they can help determine what further funding might be required to make Ontario's Action Plan a fully robust long-term plan that will lead to improved outcomes for patients, and a truly modernized healthcare system.

General Recommendation 3: Given the depth and breadth of the advice Minister Jones will need to glean from the Minister's Patient and Family Advisory Council, based on the Plan including the shared priorities and other contents of the bilateral agreements, the Minister should review the current areas of expertise covered on the Council in order to add expertise to its membership, as required.

The current membership of the Council is diverse and experienced, with specific attention focused on various therapeutic areas, mental health, equity, substance abuse, and change management. Because the breadth and depth of the strategy has expanded to include the overall modernization of the system, the Council may well require additional and specific expertise to the team. Suggested areas include health data and digital health, primary health care, and seniors' care. We also propose including patient advisors with lived experience in oncology.

General Recommendation 4: Given the breadth and depth of the potential workload associated with the priority areas, we recommend creating a list of 'alternate' Council members to act as back up for current members who may be unavailable from time to time.

General Recommendation 5: We recommend that the current membership of the Council create a process to allow for regular consultations with interested patients and stakeholders with other areas of expertise, to provide support for the advice they are providing the Minister.

This will ensure that the Council receives broad advice from a diversity of people with lived experience based on socio-demographic factors including low-income, racialized communities, housing insecurity, and Indigenous populations.

General Recommendation 6: Implementation of these investments should occur without delay.

A recent meta-analysis published in BMJ indicates that even a four-week delay in cancer treatment is associated with increased mortality.¹ We also know that in any given year, one in five Canadians will experience mental health issues.² There is no health without mental health.

General Recommendation 7: Ensure that Ontario includes processes in its Action Plan to measure and enhance patient reported outcomes, as well as patient experiences.

Minister Jones has spoken about improving patient experiences in health. We strongly support the need to improve those experiences in every way possible. Positively affecting patient experience will contribute to positively impacting patient outcomes, but the development and implementation of patient reported outcomes, those that are meaningful to patients, is also crucial. These can be developed together in a synergistic manner with the advice of expert stakeholders including patients and caregivers under the auspices of the Council.

¹ <https://www.bmj.com/content/371/bmj.m4087>

² <https://www.camh.ca/en/driving-change/the-crisis-is-real/mental-health-statistics>

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General Recommendation 8: Eliminate Trillium deductibles for people in the lowest income brackets.

While it is true that every person in Ontario struggling with healthcare costs can apply for Trillium, the deductibles remain relatively excessively high for lower income people.

Trillium applies for incomes \geq \$24,115/single individual, \$30,143/single parent, married or common-law. The minimum 4% of household income deductible is \$350/single person.

For someone barely managing, this means having to choose between purchasing food, paying rent, or taking medications. As we know, inflation exacerbates inequities, and the inflation rate in Canada is currently at levels we haven't seen in decades, if ever. Due to rising inflation, these issues have become critically important.

Important to note is that once a data-enabled healthcare system is implemented in Ontario, efforts can be increased to ensure we are collecting social determinants of health data, to facilitate evidence-based decision making in this important area.

General Recommendation 9: Ensure Indigenous community leaders and Elders are included as co-creators in all provincial health-related consultations going forward.

The UN Declaration on the Rights of Indigenous Peoples (UNDRIP) notes that Indigenous peoples should have "full and effective participation in all matters that concern them".³ In order to ensure our approach to healthcare is fully inclusive and equitable, we must uphold I/FN/M perspectives on all issues, and a 'nothing about me, without me' philosophy is warranted.

General Recommendation 10: Engage experts across stakeholder groups in aging, seniors' care, aging and living in place, and palliative care to review Ontario's current policy regarding the movement of seniors in hospital to LTC settings that may be a great distance away from the support of family and friends.

Now that there is a clearer understanding of the funding available through CHT, Ontario should take this opportunity to reconsider and potentially adapt the current policy of assigning homes for seniors. Consider broadening the membership of the Minister's Patient and Family Advisory Council to include experts in this space, as highlighted above in the recommendation.

General Recommendation 11: Consider adopting and/or adapting models of care that exist and have been validated in other jurisdictions, which would allow Ontario to hit the ground running.

Recognizing that each jurisdiction has discrete needs, priorities, and demographics, it is worth looking at best practices from around the world to see if anything is applicable, or adaptable, for Ontario.

General Recommendation 12: As part of the modernization process, the Ontario Government should set up a multi-stakeholder expert committee to consider an overhaul of the budgeting system in health.

Rather than the current service delivery model with amounts allocated to each service, a model that is population-based and bundles those services necessary for populations will provide more effective and efficient experiences and outcomes. This desired model focuses on prevention, early screening, and diagnosis, which will enhance patient outcomes and permit the use of necessary resources in under-resourced areas.

³ United Nations Declaration on the Rights of Indigenous Peoples for Indigenous Peoples. United Nations. United Nations. <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>

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PRIORITY AREA RECOMMENDATIONS

Priority Area 1: Family Health Services

Recommendation 1: Now that we understand the offer on the table from the Federal Government, we recommend that Ontario bring together experts in the area of Family Health Services, to review Ontario's proposed Action Plan to ensure we have the potential to achieve our shared objectives of providing equitable healthcare in rural and remote areas and for underserved communities. These experts will also provide advice on allocations in Family Health Services, as well as the development of measurable, transparent outcomes including timelines.

Fortunately, Ontario already has a strong base from which to build a more comprehensive and equitable provincial network of team-based primary health care. A key expert table in this area to be meaningfully consulted is the Primary Care Collaborative, whose membership includes the Alliance for Healthier Communities, Association of Family Health Teams of Ontario, Indigenous Primary Health Care Council, Ontario College of Family Physicians, Nurse Practitioner-Led Clinic Association, and the Ontario Medical Association's Section on General & Family Practice.

Additional suggested areas of expertise include health economists who focus on social determinants of health, representatives from communities that face barriers to health and healthcare including representatives from remote locations, patients and patient advocates with lived experiences, and Indigenous Elders and leaders.

Priority Area 2: Health Workers and Backlogs

Recommendation 1: Now that we understand the offer on the table from the Federal Government, we recommend that Ontario bring together experts in the area of Health Workers and Backlogs. In addition to the technical and subject matter expertise, patients and caregivers should be included to provide their real world expertise and health policy knowledge.

This Expert group would review Ontario's proposed Action Plan to ensure we have the potential to achieve our shared objectives of reducing the current strain on healthcare resources, and designing a system for the future that will eliminate unnecessary wait times altogether.

Funding must be allocated to ensure foreign trained healthcare workers are rapidly integrated into our healthcare system to tap into unused skills already in the province.

Suggested additional areas of expertise include process engineers, industrial designers, health human resource strategists, home care support organizations, etc.

Recommendation 2: To reduce the burden on our public healthcare system, Ontario should provide funding for at-home cancer medications. Doing this will directly alleviate cancer related backlogs in the system.

Cancer medications that can be taken at home (orally) provide value for the healthcare system, and for patients and caregivers. Firstly, if medications are being taken at home, patients are not required to use hospital services to receive treatment, while monitoring of patients is required less frequently, both of which reduce the burden on the healthcare system and hospitals. Secondly, for many cancer patients, making the trek to the hospital or major cancer centre for treatment is difficult, simply based on where they live. Allowing patients to access at-home medications will make life easier for them when they are at a low point in their lives. Taking at-home medications also reduces the burden of care for caregivers.

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Unlike Ontario, Western provinces cover take-home cancer drugs, regardless of age or income. In Quebec, people without private insurance pay a public premium of up to \$1,046/year, after which take-home cancer medications are covered.

Many families with private insurance lack 100% coverage, facing deductibles and/or co-pays of up to \$2,000/year. Plans have annual or lifetime caps, exceeded with cancer medication costs, disproportionately affecting older adults under 65. Economic consequences include disability, decreased productivity, and absenteeism.

Intravenous, in-hospital treatments are fully reimbursed in Ontario. By setting up the system in this way, it appears as though the province is penalizing patients indicated for at-home treatments, while at the same time, maintaining the strain on healthcare resources.

We commend the Ontario Government for recommending in the March 2022 budget the formation of an Advisory Table on take-home cancer medications. We urge the government to act on this recommendation and address this issue, for the benefit of all cancer patients.

Recommendation 3: Fund drugs and laboratory tests together, including treatment-associated tests, companion diagnostics, and genetic tests. Fund oncology laboratory tests equitably across the province to help reduce cancer test backlogs that are delaying the diagnosis and treatment of patients.

There are various ways to use genomic testing for the diagnosis of patients with cancer. Some oncology medications require testing with a “companion diagnostic” in order to determine which patients will benefit most from a specific treatment. Other genomic testing panels can be done to diagnose disease or to determine how best to treat it once it has already been diagnosed.⁴ The funding for oncology medications delivered in Ontario hospitals is fairly robust, but funding for companion diagnostics and other genomic testing lags, impacting treatment options and outcomes negatively. Health budgets allocate drugs and laboratory services separately. Pairing diagnostic tests with drugs challenges those siloed budgets.

Similar challenges exist for genetic tests and biomarker panels (panels that can test for multiple markers at the same time, and can be used to better guide treatment decisions).

With regard to equity, in most of Canada, many genomic tests and technologies are widely-available (although not always funded). Unfortunately, the access to these technologies is not equitable for Indigenous peoples, which means that FNIM patients who may need life-changing interventions, might not even know that they need them.

Although diagnostic tests such as these have a cost, these costs are offset by savings associated with providing drugs only to populations likely to respond, and disinvestment in obsolete or inferior technologies. Coordination among laboratories would avoid present duplication, providing additional cost-savings.

If health data are better connected and leverageable, disinvestment can be based on real-world evidence.

In addition, earlier diagnosis of many forms of cancers is known to improve health outcomes and survival. Rapid access to needed testing earlier in the care continuum to achieve earlier diagnosis means reduced usage of more expensive services further along the care continuum. When patients are diagnosed with cancer at a later stage, they require more treatment, surgery, radiation, specialist care,

⁴ <https://www.genomicseducation.hee.nhs.uk/blog/four-types-of-genomic-testing-explained/>

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palliative care, and other cost-intensive services, often occurring in hospital settings and resulting in wait lists and backlogs.

Recommendation 4: Fund virtual care, considering the digital equity needs of diverse populations, including high-speed internet connectivity for people in rural and remote areas, and technological literacy.

Virtual care was shown to be effective during the COVID pandemic. Just as pharmacists have recently been given an expanded scope of practice to help reduce current pressures on the system, we believe that virtual care capabilities should also continue.

Virtual care, when managed appropriately, can contribute to reducing backlogs in the system, increase access for people living outside of urban centres, and support better quality of life for patients and caregivers. We recommend Ontario reconsider the value of this service and adapt the fee schedule to reflect that immense value.

Priority Area 3: Mental Health and Substance Use

Recommendation 1: Now that we understand the offer on the table from the Federal Government, we recommend that Ontario bring together multi-stakeholder experts in the area of Mental Health and Substance Use. This Expert group would review Ontario's proposed Action Plan to ensure we have the potential to achieve our shared objectives of ensuring access to timely and quality mental health and substance abuse support in an equitable manner.

Suggested areas of expertise include representatives from CMHA Ontario, Addictions and Mental Health Ontario, Children's Mental Health Ontario, Ontario's mental health hospitals, health economists who focus on social determinants of health, representatives from minority communities, patients and patient advocates with lived experiences, and Indigenous Elders and leaders.

Recommendation 2: Ensure that appropriate priority is given to community-based mental health and substance use services, including specific allocations for children and youth mental health services. This will strongly improve the current backlogs in the delivery of these important community-based services.

Priority Area 4: A Modernized Health System

Recommendation 1: Now that we understand the offer on the table from the Federal Government, we recommend that Ontario bring together multi-stakeholder experts in the area of Health System Modernization. This Expert group will review Ontario's proposed Action Plan to ensure we have the potential to achieve our shared objectives of a truly data-enabled healthcare system that is designed for the future of healthcare.

Suggested areas of expertise include health data policy, innovation policy, data scientists, data infrastructure, data governance, cyber security, electronic medical records, interoperability, members of the Expert Advisory Group to the Pan-Canadian Health Data Strategy, representatives from the First Nations Information Governance Centre, patients, patient advocates with lived experience and expertise in health data, members from the Policy Modernization Group, strategists, and Indigenous Elders and leaders. There are a number of patient and caregiver experts that are part of an existing Data Working Group convened through the Patients Redefining the Future of Healthcare in Canada Summit that would be pleased to contribute.

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Recommendation 2: Address the need for shared health data in Ontario by supporting and implementing a consistent, common, transparent, pan-Canadian health data strategy in collaboration with Canadian provinces and territories (refer to the [Expert Advisory Group pan-Canadian Health Data Strategy Overview – Canada.ca](#)).

The successfully-implemented strategy will facilitate a connected, comprehensive, secure, and transparent data ecosystem that will enhance the ability to improve the quality of patient care and the achievement of better health outcomes, understand disease impacts, produce and adopt innovations in health, and deliver care more seamlessly and sustainably. Included within this recommendation is the funding of high-speed internet throughout the entire province, to ensure equity of access for all.

Central to achieving this strategy is providing people, providers, system administrators, and researchers better access to real-time health data. In particular, people need to be able to easily access all of their personal health data and their data must follow them, not remain locked in provider or jurisdictional systems.

Ontario has been one of the leading provinces contributing to the development of a pan-Canadian health data strategy and we commend you for that leadership.

As we are sure the province has recognized, especially with the recent experience understanding and responding to the COVID pandemic, in order for the benefits of integrated health data infrastructure to be maximized, the data must not live in provincial or provider siloes. Shared infrastructure that works for and in Ontario, as well as with the entire country, is essential. Once these data are connected and interoperable, data must be leveraged to improve the care we each receive, to improve publicly funded healthcare, and to improve research and innovation that will have public benefits.

We recognize that each province is at a different place in terms of how far it has gotten in developing its unique data management strategies so each will need solutions specific to its needs. Ultimately, however, the vision and foundational pillars should be the same across the country. The Canadian public depends on this.

We, therefore, echo the calls from various patient organizations, think tanks, and healthcare coalitions to continue to work together with your federal, provincial, and territorial colleagues to meet each of your individual needs and the collective needs of people in Canada.

We urge you to support and implement a consistent, common, transparent, pan-Canadian data strategy with interoperable architecture so that the people who live in Canada are able to both easily access their data, and have their data follow them no matter where they live or travel in Canada.

In doing so, the province of Ontario will help ensure that we are able to leverage meaningful data at scale to make evidence-based health and policy decisions.

Recommendation 3: Ensure that patients and patient representatives are included in conversations about modernizing Ontario's health data system to ensure that real needs and gaps are being addressed.

Patients must be a central part of the collaborative efforts to modernize health data.

Recommendation 4: Ensure provincial government Data Stewards and Custodians are educated and certified in the First Nations principles of ownership, control, access, and possession of data (OCAP[®])⁵

⁵ <https://fnigc.ca/ocap-training/>

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In order to ensure our approach to healthcare is fully inclusive and equitable, Ontario must uphold FNIM principles on data sovereignty, and a 'nothing about me, without me' philosophy is warranted. It behooves us to learn more about the principles that guide the way to think about Indigenous health data from established Indigenous data experts like the First Nations Information Governance Centre.

Recommendation 5 Allocate a portion of the CHT to transform and modernize healthcare systems and policies, supported by better data and information, to be proactive, emphasizing prevention, promotion, earlier diagnosis and care, creating specific strategies for cancer, mental health, older adult services, and other diseases under-resourced pre-COVID.

Bring experts in longevity, prevention, primary health care, public health, early diagnosis, and wellness together to provide expert advice to the province on how Ontario can be a leader in prevention, health promotion, and earlier diagnosis.

A truly innovative and forward-looking healthcare system will recognize that an ounce of prevention is worth a pound of cure. Discrete funding would allow Ontario to begin the transition from sick care to well care, thereby delaying and/or preventing diseases in the future, and demonstrating thoughtful leadership for other provinces and territories.

A connected, data-enabled healthcare system will facilitate insight generation to assist in planning related to prevention activities.

Recommendation 6: Overall, make health priorities transparent, sustainable, with measurable outcomes co-created with patients, with results published in a variety of formats, including online, in real time.

Transparency in reporting will allow Ontario to identify promising and best practices, learn from local experts who have achieved success, and adopt and adapt those practices as appropriate.

All CHT funding should have a transparent trail from funding to outcomes. Transparency will allow us to 'raise and praise' best practices across the country. If outcomes aren't changing positively, a pivot in strategy could be warranted. Transparency will facilitate agility and rapid learning.

Recommendation 7: Allocate surveillance and public health resources to prepare for potential health crises and create an integrated, proactive response.

Leverage connected data infrastructure to inform evidence-based recommendations and public health resource allocation. Ensure levels of interoperability internationally to ensure data sharing is possible in pandemic situations.

Recommendation 8: Allocate a portion of the CHT toward health data literacy activities.

Bring experts in data literacy and plain language, including patient experts, together to provide advice to the province on how Ontario can play a role in establishing foundational health data literacy for its citizens, thereby giving them agency to participate in their own healthcare decision making.

It is essential that citizens of Ontario achieve a foundational level of health data literacy. They must understand that they own their personal health data, how data relates to information, that they have the right to control their own information and to share it to achieve better health outcomes.

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Recommendation 9: Engage patients, patient advocates, people that face barriers to health and healthcare, including FNIM, racialized, Francophone, LGBTQ, health equity experts (including EMPaCT⁶), as well as the Ministries of Housing, Social Service, Justice, Seniors & Accessibility, and Long-Term Care to advise on data-driven methods to enable a more equitable Ontario healthcare system.

Building on work done to date, this must include specific plans on how to appropriately and consistently collect and analyze social determinants of health data across the province.

COVID has demonstrated and exacerbated health inequities. It is vital to finally improve data collection to consistently include common socio-demographic factors so all information can be disaggregated to understand specific health inequities, and identify opportunities for improvement.

Increasing the quality and robustness of properly disaggregated data collected, analysed, and leveraged in Ontario will help ensure social determinants of health are understood and addressed in a robust manner. Once the data is inclusive, it can be leveraged to better understand inequities. Seek advice from experts on how best to implement a plan toward a 10-year goal of making Ontario the most equitable province in terms of health outcomes and access to healthcare for everyone in the province.

Recommendation 10: Consider modernizing policies to facilitate the creation and adoption of health innovations.

It is time to bring innovation policy to the forefront of Ontario health policy discussions to better support the start-up community, and to ensure that issues such as Intellectual Property aren't getting in the way of better health outcomes for patients. In doing so, we will strengthen both the health potential for people in Ontario, as well as the economic growth for our province, and will demonstrate that investments in health innovations can lead to improved health outcomes.

Other Recommendations:

Recommendation 1: Fund and implement vaccination programs in Ontario schools to ensure that all necessary vaccines are easily accessible to students (for example, HPV vaccines).

Included in this prevention bucket are vaccination programs for Ontario students. COVID highlighted the difficulties some people experience when attempting to access vaccines and other preventative health services. Bring the medicines to the people.

Recommendation 2: Fund rural/remote travel for patients as required, including for diagnostic investigations.

We thank you for the opportunity to provide our thoughts.

Sincerely,

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⁶<https://www.longwoods.com/content/26768/equity-mobilizing-partnerships-in-community-empact-co-designing-patient-engagement-to-promote-hea>

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