

Written Submission for the Federal Pre-Budget Consultations
By National Patient Organizations signatory to this submission

February 10, 2023



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FOUNDATION



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MYELOMA
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Canadian Skin Patient Alliance
Alliance canadienne des
patients en dermatologie



CANADIAN CANCER
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LSTN

Life-Saving Therapies Network

Connecting people and organizations concerned about better therapies and faster access

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

General Comments

We commend the Federal Government for recognizing the need for increases to Canada Health Transfer payments with an increase in the CHT floor from 3% to 5% for the next five years as a start.

We support the list of identified shared priorities and note that they are among those that we are hearing from patients across the country as crucial for improvement given the dire state of the healthcare system.

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 the Premiers and the Canadian Medical Association, among others, that more investment is required for true modernization of our healthcare system. To that end, it will be critically important to ensure that all upcoming decisions regarding resource allocation and priority areas in the provinces and territories are inclusive in terms of seeking expert advice.

We are encouraged to see that a portion of CHT is being allocated for specific bilateral agreements with the provinces. We encourage the Federal Government to help steward the process along by keeping the provinces and territories accountable for using the CHT directly for healthcare, rather than allowing the funds to move to general revenue. We also encourage the inclusion of various stakeholders, including patients and caregivers, in any bilateral discussions, to ensure multiple perspectives are considered.

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 long-term strategies that will modernize our system for the future, so we can overcome the healthcare crises we are now experiencing and prevent future crises. Equally important to the funding to achieve healthcare modernization are long-term, collaborative processes that must be established to help stakeholders work together towards sustainable improvements in all priority areas. Just as Canada's inter-jurisdictional collaboration was central to our nation's effectiveness in adapting and responding to the COVID pandemic, everyone living in Canada will benefit from ongoing collaboration, coordination, sharing, and learning across Canada's jurisdictions. To successfully modernize healthcare means working together over the long-term, not just during public health crises.

Tracking the investments into healthcare and being transparent about the results, whether positive, negative, or both, will be foundational to the success of modernizing Canada's healthcare system, and will help ensure the public is (and remains) onside. It will be important to ensure there are measurable outcomes co-created with patients for the shared priorities, with results published in real-time through various channels, digital and otherwise. 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 Canada's healthcare systems. This information flow, combined with sustained processes for F/P/T collaboration, will create the conditions for a Canadian learning health system.

While the federal plan will assist in short-term solutions to the immediate crises in the healthcare system, true modernization of the healthcare system requires a complete overhaul of the strategy for funding and delivering healthcare, as well as the recognition of the need to include social determinants of health in all discussions around budgeting. Taking a 'health in all policies' approach when allocating funds will support better decision making. A fulsome discussion with all relevant stakeholders, including First Nations, Inuit, and Métis (FNIM) representatives, on how to make our modernized system future-proof and resilient is warranted. The focus must be on health outcomes across the continuum of care, not outputs produced by siloed service providers.

For your consideration, full participation from the provinces and territories in the proposed tables and discussions, as well as abiding by transparent reporting, could be conditions of funding, to help ensure that taxpayer funding will result in the modernized healthcare system we all deserve.

Finally, as discussed below with regard to *Priority Area 4: A Data-Enabled Modernized Health System*, we recommend that the Public Health Agency of Canada and the Canadian Institute of Health Information should hold accountability for overseeing the implementation of the third report of the Pan-Canadian Health Data Strategy's Expert Advisory Group, including establishing a common vision and pillars for a learning health system.

GENERAL RECOMMENDATIONS

Recommendation 1: To create a truly modernized approach to healthcare system funding and delivery, the Federal Government should convene a pan-Canadian, multi-stakeholder group to develop and present a binding strategy and tactics to achieve the vision of a truly modernized healthcare system.

The multi-stakeholder group should include those with expertise in health system management, data governance, data infrastructure, data science, data policy, data management, healthcare economics, human rights, health justice and ethics, social determinants of health, Indigenous populations, rural and urban populations. The group should also include experts from each of the shared priority areas, including expert patients with lived experience, and participation from all political perspectives.

The strategy and tactics should be agile, to ensure flexibility, resiliency, continuous learning, and iteration, and to make real-time adaptation feasible.

Recommendation 2: Facilitate ongoing convening and collaboration of the Federal Government, provinces, and territories to support cross-jurisdictional learning and, where appropriate, alignment, as the provinces and territories implement the shared priorities.

Federal, provincial, and territorial collaboration was the most fundamental source of strength in Canada's response to COVID. Cross-jurisdictional collaboration builds on the legacy of the leadership of past Liberal governments, which was the basis of much progress on common F/P/T priorities in the past, and is needed now more than ever as our healthcare systems are in a sustained crisis.

Recommendation 3: Ensure ongoing review of CHT to account for inflationary factors and adjust accordingly such that the transfers at least match inflation.

CHTs are generally provided as flat rate transfers. Given current economic and environmental circumstances, it must be ensured that the health transfers can keep up with inflationary pressures.

Recommendation 4: Provide impartial funding for patient groups to meet growing demands for meaningful patient representation by governments and other stakeholders in decision making processes.

Patient groups working directly with diverse patient populations need to retain the ability to engage in all work that affects their membership (patients). These groups need sustainable resources to replenish resources lost due to the pandemic, and to meet the growing demands for meaningful patient representative engagement by governments and other stakeholders.

A fund should be established with transparent, objective eligibility criteria set by these types of groups, and administered by an independent, multi-stakeholder committee to which such groups can apply to augment their limited resources to permit them to represent patient groups meaningfully in a broad range of fora.

Recommendation 5: Take a 'health in all policies' approach to ensure that all aspects of the budget are analyzed through a health equity expert lens and adjusted accordingly.

Health inequities continue to grow due to worsening social determinants of health and widening inequalities in healthcare access across the country. This must be considered in all aspects of budgetary health planning.

As mentioned in the preamble, while the federal proposal will assist in short-term solutions to the immediate crises in the healthcare system, true modernization of the healthcare system requires a complete overhaul of the strategy for funding and delivering healthcare, as well as the recognition of the need to include social determinants of health in all budgeting decisions.

Recommendation 6: Lead and fund a comprehensive review of all healthcare and related federal agencies, departments, and other government boards and programmes to remove duplication and red tape.

Fund a multistakeholder, comprehensive review of Federal Government Ministry of Health systems and federally funded organizations with mandates affecting healthcare to ensure that duplication of activities are removed and unnecessary processes that do not add value, often referred to as red tape, are removed. Funds saved in this process should remain in relevant budgets for reinvestment.

PRIORITY AREA RECOMMENDATIONS

Priority Area 1: Family Health Services

Recommendation 1: The Federal Minister of Health should convene an F/P/T table on Family Medicine/Primary Healthcare.

The table should include relevant experts at the national level to establish goals, outcomes, objectives, and tactics associated with this priority area, to share promising and best practices and leverage learning and improvement in primary healthcare across the country. Patients and caregivers with lived experiences should be partners in this work.

Suggested groups include, but are not limited to, the Canadian Medical Association, the Canadian Nurses Association, the Nurse Practitioners Association of Canada, the Canadian Pharmacists Association, the Canadian Association of Social Workers, the Canadian Association of Community Health Centres, the Association of First Nations Health Managers, All.Can Canada and other groups with insights into opportunities to modernize family medicine and primary healthcare and better support primary healthcare to swiftly connect with secondary, tertiary, quaternary, and acute care.

The participants should work with CIHI on common, country-wide primary healthcare outcomes, indicators, and socio-demographic data collection for data disaggregation.

It is critically important that we approach these issues at a national level, to ensure that local learnings can be adapted and leveraged across jurisdictions, human resources can be planned for appropriately across all of Canada according to need, and to support equitable and effective approaches to team-based primary healthcare.

Recommendation 2: Develop and implement a Universal Pharmacare Plan and a Universal Dental Plan that, together, ensure equitable access to treatments for all people living in Canada.

This would serve to help achieve the shared objective of providing equitable health and dental care in rural and remote areas, and for underserved communities. Discussions should include

relevant experts at the national level to share promising and best practices across the country and should take into consideration programs in other jurisdictions which may be helpful in informing a strategy for Canada.

Priority Area 2: Health Workers and Backlogs

Recommendation 1: The Federal Minister of Health should convene an F/P/T table on Health Workers' Recruitment & Retention.

The table should include relevant experts at the national level to establish goals, outcomes, objectives, and tactics associated with this priority area, to share promising and best practices and leverage learning and improvement in health and human resources across the country. Patients and caregivers with lived experiences should be partners in this work.

Suggested groups include, but are not limited to, the Canadian Medical Association, the Canadian Nurses Association, the Nurse Practitioners Association of Canada, the Canadian Association of Community Health Centres, the Association of First Nations Health Managers, Black Physicians of Canada, the Canadian Pharmacists Association, the Canadian Association of Social Workers, and other allied health professional associations.

The participants should work with CIHI on common, country-wide health human resources outcomes, indicators, and socio-demographic data collection for data disaggregation.

It is critically important that we approach these issues at a national level, to ensure that human resources can be allocated appropriately across all of Canada according to need, and to support equitable approaches in treatment.

Recommendation 2: Work with the provinces and territories to ensure continuation of funded 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. Ensure the Minister of Innovation is funded and held accountable for achieving Canada-wide high-speed internet connectivity, including in rural and remote parts of the provinces and territories.

Virtual care was shown to be effective during the COVID pandemic. 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 the Federal Government work with the provinces and territories to prioritize the value of this service and adapt their funding models to reflect that value. In addition, hold the Minister of Innovation accountable and ensure the Ministry is appropriately funded to deliver on investments in high-speed internet connectivity for everyone in Canada.

Priority Area 3: Mental Health and Substance Use

Recommendation 1: We recommend that the Federal Minister of Mental Health and Addictions continue the excellent work of her ministry in building a mental health strategy that “everyone can see themselves in.”¹

We commend the Minister for the work implemented to date and we encourage the scaling of the integrated model of care across the country, to achieve the cohesive model of care that is desired and optimal. As part of that work, we support the creation of national standards related to the treatment of mental illnesses and substance abuse.

We propose that in addition to the promising work being undertaken, the Minister should convene an F/P/T table on Mental Health and Addictions to establish goals, outcomes, objectives, and tactics associated with this priority area, to share promising and best practices and leverage learning and improvement in mental health and substance use across the country. Relevant Mental Health and Addictions experts at the national level should be included at this table. Patients and caregivers with lived experiences should be partners in this work.

Suggestions include but are not limited to the Mental Health Commission of Canada, the Canadian Mental Health Association, the Canadian Association of Psychosocial Oncology, Institute for Advancements in Mental Health, and Jack.org who are focused on youth mental health.

The participants should work with CIHI on common, country-wide mental health and substance use outcomes, indicators, and socio-demographic data collection for data disaggregation.

Establishing clear, agreed-upon outcomes and measures, with data disaggregation, will help ensure equity of care and outcomes across the country. Robust data sets that include socio-demographic data from underserved and diverse communities will help ensure no patient is left behind.

Priority Area 4: A Data-Enabled Modernized Health System

Recommendation 1: As highlighted at the beginning of this submission, we recommend that the Public Health Agency of Canada and the Canadian Institute of Health Information should oversee the implementation of the third report of the Pan-Canadian Health Data Strategy’s Expert Advisory Group, including establishing a common vision and foundational pillars for a learning health system.

Support is required for the provinces and territories to ensure they are able to take the recommended next steps toward building a truly data-enabled healthcare system that puts the

¹ <https://mentalhealthcommission.ca/catalyst/a-conversation-with-canadas-first-minister-of-mental-health-and-addictions-carolyn-bennett/>

person at the centre of care. Please refer to the third report from the Expert Advisory Group [here](#).

These bodies should play a leadership role in ensuring the appropriate allocation of resources to each priority area, and to the stakeholders who will be involved in implementation. Ensuring alignment and coordination of common goals, outcomes, objectives, and tactics such as demonstration projects towards a common vision of Canada's learning health system will facilitate a truly robust pan-Canadian approach to achieving a data and information-enabled healthcare system, sustainably resolving the current healthcare crises, preventing future ones, and increasing readiness for future pandemics or other unexpected healthcare crises.

Recommendation 2: The Public Health Agency of Canada and the Canadian Institute of Health Information should be appropriately funded to ensure full accountability for providing leadership on implementation.

Without appropriate funding for specific activities in support of implementation, the strategy will fail.

Recommendation 3: As part of their stewardship role, the Public Health Agency of Canada and the Canadian Institute of Health Information should collaborate in the development of health data literacy strategies and activities for the Canadian public as part of the implementation of the Pan-Canadian Health Data Strategy.

To start, convene a Public Assembly of experts in data literacy and plain language, including patient experts, to provide strategic leadership for provinces and territories on how they can play a role in establishing foundational health data literacy for people who live in Canada. Increased data literacy will empower people and give them agency to be able to participate in their own healthcare decision making.

People who live in Canada must understand that they own their personal health data, how data relates to information, that they have the right to control their own information as well as to share it to achieve better health outcomes and support improved health and healthcare for everyone in Canada.

We encourage these organizations, as well as Canada Health Infoway, to build on health data literacy materials that are already validated, while also seeking innovative ways to expand the knowledge base leveraging digital and non-digital tools.

Recommendation 4: As part of their stewardship role, the Public Health Agency of Canada and the Canadian Institute of Health Information should work with stakeholders to create a common, shared definition of health data, as well as a determination of what data should be collected, and how.

This would lead to core elements like standards development toward higher quality data, aligned data collection methods to provide assurance that we are collecting relevant and meaningful data, and data audits to continually check the quality of data. If we focus simply on data sharing, without thinking critically about how to improve the quality of the data we are sharing, little benefit will be gained as bad data will lead to bad, poorly-informed, and even harmful decisions.

As we strive toward our shared vision of a modernized, data-enabled healthcare system, a pan-Canadian approach that recognizes the needs of each province and territory while enabling safe and appropriate data flow across settings and jurisdictions is essential.

Recommendation 5: As part of the modernization process, the Federal Government, in collaboration with the Public Health Agency of Canada, the Canadian Institute for Health Information, the First Nations Data Governance Centre, other experts in Indigenous data governance, provinces and territories should bring together an FNIM data table to ensure that Indigenous data sovereignty is built into the implementation of the strategy.

Refer to the pan-Canadian Health Data [Strategy](#) for more information.

Recommendation 6: Allocate surveillance and public health resources to prepare for potential health crises and create an integrated, proactive plan so that we are well-prepared for the next pandemic.

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. Take an agile approach to ensure that the plan is flexible, resilient, and sustainable.

Recommendation 7: Develop a comprehensive and sustainable pandemic plan, including surveillance, to enhance Canada's capability to respond efficiently and effectively to infectious disease crises.

The Federal Government must lead a multi-stakeholder, pan-Canadian review of the pandemic plan including diverse patient group representatives. The mandate will include an overhaul of NACI, further support for G-PHIN, and the development of a resilient healthcare system strategy to enhance Canada's capability to respond efficiently and effectively to infectious disease crises, including those arising from natural emergence, climate change, animal husbandry and biological warfare.

Funding must come from a discrete budget allocation.

Other Recommendations:

Recommendation 1: Augment supports to eliminate child poverty in Canada.

Canada is one of the most economically advanced countries and a member of the G7. Yet there are still high rates of child poverty particularly among Indigenous peoples, single-parent households led by women, and new Canadians. The Federal Government must ensure that leadership and resources are provided to end child poverty, led by the populations directly impacted and the experts they recommend for support. Child poverty can contribute in a negative way to both physical and mental health.² Starting out in life at a deficit leads to poorer health outcomes in adulthood. We support the recommendations of the 2022 Report of the National Advisory Council on Poverty and encourage the Federal Government to implement the recommendations in that [report](#).

Recommendation 2: Augment supports to eliminate homelessness in Canada.

As reinforced through a recent report from Public Health Ontario, there are specific and often serious negative health outcomes associated with homelessness. The report highlights infectious diseases (e.g., STIs), mental health issues (including substance abuse, cognitive impairments), chronic illnesses (e.g., diabetes), and injuries.³

There is an urgency to modernize the health data infrastructure in Canada. Data about the unhoused and corollary issues related to being unhoused, including those related to mental health and substance use, will help inform a robust strategy to eliminate homelessness in Canada, thus “...eliminating the increase in health-related issues related to being homeless.”⁴

Recommendation 3: We encourage the Federal Government to convene an expert group led by Indigenous populations, to develop an Indigenous cultural and languages translation strategy for communicating about topics related to health, healthcare, and health data.

The discussions should include experts in health and health data literacy, plain language, Indigenous patients, representatives from the First Nations Information Governance Centre, as well as representatives from the Indigenous Primary Health Care Council, Indigenous Elders and leaders, and all other relevant and interested stakeholders.

Many providers and stakeholders publish (either digitally or on paper) health information. This might include information about how to navigate our healthcare system, information about medicines and diagnostic tests, or information about diseases. Most of these materials are never published in Indigenous languages, which leaves many people underserved. In addition,

² <https://canadianfeedthechildren.ca/>

³ <https://www.publichealthontario.ca/-/media/documents/E/2019/eb-homelessness-health.pdf>

⁴ Ibid.

many materials may benefit from not only language translation but also cultural adaptation to be more effective for the hundreds of different nations across Turtle Island.

The United Nations General Assembly proclaimed the decade of 2022 and 2032 as the International Decade of Indigenous Languages. Their goal is “...to draw global attention to the critical status of many Indigenous languages around the world and to mobilize stakeholders and resources for their preservation, revitalization and promotion.”⁵ The cost of adapting and translating materials for diverse Indigenous audiences is cost-prohibitive for many organizations, including many large ones. Federal leadership in this area could create opportunities for collaboration between multiple stakeholders to work toward making materials available in Canada’s original languages.

Recommendation 4: Continue to fund and augment an equitable, sustainable, cohesive, federal plan for cancer management, to adequately address the profound impacts of increasing cancer incidence and prevalence. In addition, expand involvement in Project Orbis to ensure faster access to innovative cancer treatments in Canada.

The issue of late cancer diagnoses is now also a backlog issue across the entire country. The expected tsunami of late-stage cancer diagnoses will contribute negatively to backlogs.

Augment funding for the implementation of a national cancer strategy that is effective, efficient, equitable and inclusive. This includes ongoing support for the Canadian Partnership Against Cancer (CPAC) and funding the creation of a group including CPAC, Healthcare Excellence Canada, All.Can Canada, diverse patient representatives, and other diverse healthcare stakeholders to ensure a cohesive, sustainable approach to cancer management, especially in the context of increasing cancer incidence and prevalence, increase in late-stage cancer diagnoses due to delays, and an aging population disproportionately impacted by cancer.

Project Orbis provides a framework for concurrent submission and review of oncology products among participating international partners, aiming to deliver faster patient access to innovative cancer treatments. This recognizes the incidence, prevalence, morbidity and mortality of cancer, and the benefit of early treatment access to innovative treatments with potential benefits over existing therapies.

Currently, the pan-Canadian Oncology Drug Review (pCODR), housed within CADTH, provides recommendations for public reimbursement of cancer therapeutics. The establishment of a separate review process for oncology therapeutics was based on the recognition by the Standing Committee on Health of the need for a discrete oncology review process, in its report issued December 2007.⁶

⁵ <https://rcgs.org/indigenous-languages/#:~:text=The%20United%20Nations%20General%20Assembly,and%20resources%20for%20their%20preservation%20>

⁶ <https://www.ourcommons.ca/DocumentViewer/en/39-2/HESA/news-release/3184245>

The federal/provincial/territorial Deputy Ministers of Health transferred oncology HTA processes to CADTH effective April 2014, with a separate stream for oncology drugs through the pCODR process that had been in place prior. CADTH committed to maintain discrete processes for oncology.

CADTH merged the pCODR processes with its Common Drug Review (CDR)⁷, leading to reduced access to innovative cancer therapeutics, contrary to the purpose for establishing pCODR and the principles of Project Orbis.

The mandate and the processes within pCODR should be amended to align with Project Orbis and best practices internationally. An alternative will be to extract the process for oncology review from CADTH and provide the independent process with a new mandate, aligning with Project Orbis.

Recommendation 5: Ensure Indigenous leadership in all aspects of the Federal Government's response to Indigenous health issues, and provide resources as required.

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”.⁸ In order to ensure Canada's approach to healthcare modernization supports reconciliation, we must uphold FNIM perspectives on all healthcare issues, and a ‘nothing about us, without us’ philosophy is warranted.

We thank you for the opportunity to provide our thoughts.

Sincerely,

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⁷ <https://www.cadth.ca/news/cadth-announces-aligned-drug-reimbursement-review-process>

⁸ <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>