



Submission to Canada's Fundamental Science Review

Executive Summary and Recommendations

Executive Summary

The federal government's review of fundamental research funding presents an important opportunity to develop a more inclusive health research agenda that reflects the experiences of Canadian patients,¹ researchers and health charities.

Fundamental research is imperative to improving the lives of patients as it opens up new avenues of discovery and improves the shared knowledge base. Disproportionate emphasis on applied research in recent years' risks limiting how Canada approaches pressing problems and reducing knowledge of how Canadians are impacted by health conditions. Health research funding must strike a balance between basic and applied research in order to fuel advances that can improve the lives of patients now and into the future.

The Health Charities Coalition of Canada (HCCC) is a member-based organization comprised of national health charities who represent the voice of patients at all levels of the health continuum.² Our mission is to facilitate the collaboration of Canada's health charities to achieve excellence in health policy, practice and research. Annually, our members invest over \$200 million in health research. Over 13 million Canadians receive direct service from us each year and look to us for information, assistance and leadership in health policy and health research.

Many of the investments that health charities make and the researchers that the sector employs and funds require active and ongoing partnerships and collaborations with the federal government's research granting councils, especially the Canadian Institutes of Health Research (CIHR).

A strong health research ecosystem relies on adequate funding for patient-driven research balanced across multiple elements, including reliable support for fundamental science research. The purpose of this submission is to share a range of perspectives from among our members on the funding of science in Canada. Health charities want to work actively with the panel and the granting councils on this review and to implement reforms that are already underway. Our ultimate goal is to create a world-class Canadian research ecosystem.

The role of health charities in funding research is substantial, not only in terms of financial contributions, but also in its investment in new researchers and its focus on building capacity and attracting talent to particular health fields. Research funded by health charities often addresses areas that might not be prioritized by government or private industry, but which are important to Canadians affected by particular diseases. This is a result of direct engagement with and direction from patients who are served by health charities in Canada and who in turn support them with gifts of time and treasure.

¹ We have used the term "patients" in this document to mean a broad category of people in Canada, including those actively interacting with the healthcare system and those who have in the past, those living with diseases, disabilities and mental health issues, and those who care for and support them, such as their families, friends and communities.

² A full list of our members can be found on our website at www.healthcharities.ca.

Our members fund research projects that address lung disease, cancer, dementia, cardiovascular disease, diabetes, arthritis, kidney, bone and joint disease, rare diseases including cystic fibrosis and blinding eye diseases, degenerative diseases including Huntington disease, and neurological and neuromuscular disorders, such as amyotrophic lateral sclerosis (ALS). In addition to biomedical and clinical research, health charities fund health services and policy research that supports patient care.

Responsive federal funding of fundamental research in Canada includes health charities as key partners of government, universities and private industry. Enhanced coordination and collaboration among these four key catalysts would enable the hundreds of millions of dollars invested annually in research by health charities to be boosted by public and private investment. Better organization and administration that supports the full breadth of health research activity and works with health charities will benefit Canada's health research ecosystem.

The recommendations of patient communities and the health charities that represent them should guide any reform of research funding priority setting, governance, operations and ongoing engagement. To this end, HCCC remains available to work with the federal government throughout its review and any resulting reform.

RECOMMENDATIONS

The Health Charities Coalition of Canada (HCCC) submitted recommendations related to four key objectives.

A. Putting patients at the centre of the health research ecosystem

Patients have a unique lived perspective and must be continuously involved in shaping the health research agenda. The perspectives of patients, their caregivers and healthcare providers should inform federal research funding programs, as they are the individuals that our health systems are designed to serve. Patients and their caregivers' diverse health research experiences and their preferences are reflected in their support of research by health charities and these priorities should inform the broader health research agenda in Canada.

The federal government should also draw on the leadership of health charities in setting research agenda priorities. Health charities use many approaches to shape the health research agenda, including direct engagement with patients and international collaborations. Health charities are also knowledge brokers who provide regular knowledge translation to patients, clinicians, decision-makers, and other healthcare stakeholders that help contextualize research outcomes and important advances both domestically and on an international scale.

Recommendations:

1. Meaningfully engaging patients in setting health research policy.
2. Enhancing current methods of research agenda priority setting to include patients and health charities.
3. Drawing on the expertise of health charities in knowledge translation to patients, caregivers and healthcare providers.
4. Coordinating research priorities with those established by patients and the health charities that support them by leveraging direct citizen engagement.

B. Restoring health research funding in Canada

Restoring funding for health research in Canada is vital to ensuring that our researchers have adequate resources to continue to drive important advances and improve the lives of patients. Sustained budget pressure has resulted in very promising research remaining unfunded. Investments in research today provides jobs and stimulates the economy, setting the stage for improved health outcomes, prosperity and innovation in the future. The research ecosystem relies on many components and funding must be balanced across operating funds, infrastructure and salary support. In the absence of adequate operating funding, many research studies – which may lead to important discoveries – remain unexplored.

Recommendations:

5. Restoring adequate funding for health research and supportive knowledge translation programming by increasing federal spending on health research to 1% of total health spending in Canada, consistently and reliably over the next 10 years.
6. Providing a pathway for researchers to pursue funding for investigator-led research through federal granting councils that promotes the exploration of new concepts, processes and technologies that may lead to cures or improvements in treatment or care for patients.
7. Leveraging the considerable investment of Canadian health charities in research by including them in the funding formula of the Research Support Fund – or provide such funds through an alternate federal mechanism – to ensure that peer-reviewed research funded by national health charities is treated equally to research funded by the federal Tri-Councils.
8. Ensuring that funding is balanced across elements of health research.
9. Ensuring that dedicated, predictable and sustained funds are available to support all the pillars of health research in Canada, including biomedical, clinical, health systems research, and social, cultural and environmental and population health research.

C. Making CIHR more effective

Recent reforms at CIHR have changed how the agency operates, impacting health research priorities and the working relationship between the CIHR and community organizations, such as health charities. Where those reforms have resulted in a diminished patient voice or research priorities that do not align with patient needs, a different approach must be implemented.

Granting councils that focus on distinct areas of research, as is currently the case with the Tri-Councils, should be preserved but could be made more efficient and collaborative. The institutes model used by CIHR enables research funding decisions to be made strategically to advance research agendas across different disease and policy areas and should be maintained. Each Institute Advisory Board provides ongoing relationships with patient communities and their health charities and are crucial to ensuring alignment in the health research agenda across different disease and policy areas. Health research funding applications must be reviewed by peers who are familiar with the subject matter of the application.

Health charities collectively contribute over \$200 million annually to health research and the federal government should leverage these contributions and develop a comprehensive approach that includes health charities as formal partners, including through citizen engagement and health charity coalitions. Coordination of funding and research objectives within and across Canada's research ecosystem would boost investment and research productivity

Recommendations:

10. Maintaining the current institutes model of CIHR in which the institutes are the predominant mechanism to determine strategic priorities.

11. Restoring a robust Institute Advisory Board model that aligns with each institute, that involves patients and health charities on an ongoing basis and that serves as a dedicated source of expertise and infrastructure for different disease and policy areas.
12. Ensuring that there remains a specific arm's length agency focused on health research that is accountable to the Minister of Health.
13. Ensuring that different disease and policy areas are not disadvantaged as a result of the research funding model.
14. Developing a comprehensive approach that includes health charities as funding partners, such as through formal partnerships.
15. Ensuring that research funding decisions are made on a strategic basis, not a purely financial basis.
16. Ensuring that peer reviewers have relevant expertise.

D. Supporting young researchers

Researchers should be actively supported throughout their careers and especially as they begin to develop their own teams and pursue lines of enquiry that they have identified. Support for young researchers is crucial to attracting and retaining research talent in Canada.

Recommendations:

17. Ensuring that young researchers receive adequate support to continue to develop into leaders, including operating grants, salary support and access to appropriate infrastructure.
18. Reinstating career development programs for researchers – in particular, reinstating the M.D./Ph.D. support program.