



ADVANCING THE NATIONAL FRAMEWORK FOR DIABETES

Investing in Canadians living with type 1 diabetes
JDRF Canada

Recommendations

Recommendation 1



The Government of Canada should invest \$30M over 5 years with JDRF Canada (with a minimum of \$5M in financial or in-kind match funding from other funders of trials) to support a type 1 diabetes (T1D) Clinical Trial Network to enable up to 7 high-impact trials, infrastructure to accelerate the planning and launch of new trials and trial sites, and training of multiple new clinician-researchers. Funding will also support expansion of a key enabler of the T1D Trial Network, a platform co-designed by patients to engage the T1D community in research, accelerate trial recruitment and collect and report on national T1D data.

Recommendation 2



The Government of Canada should invest \$5M over 3 years into implementation research on interventions that addressing mental health challenges in people with T1D.

Introduction

With approximately 30 Canadians diagnosed daily, type 1 diabetes (T1D) is an autoimmune disease affecting an estimated 300,000 people across the country. Until a cure is found, people with T1D rely on insulin to survive. But insulin is only a treatment, and Canadians with T1D have a life expectancy that is 10 years less than the general population.

The global rate of T1D is climbing by 4.4% every year – faster than general population growth of 1.2% per year – and we do not know why. At this rate, the number of people living with T1D is expected to more than double every 20 years.

T1D occurs when the pancreas cannot produce enough insulin for the body’s needs, causing blood sugars to rise. People with T1D monitor their blood sugar throughout the day and take insulin via injections or an insulin pump. It has been estimated that a person with diabetes makes up to 300 decisions daily about their disease management, straining an individual’s mental health.



Health care costs resulting from diabetes in Canada were estimated to reach over \$16.9 billion (CAD) annually by 2020. The need is urgent to develop and test new therapies to reduce disease burden, as well as to collect T1D data that can be leveraged to improve care and outcomes.

JDRF Canada is grateful that the government has made investments to ease the physical, mental and financial burden that T1D has on so many Canadians.

Last year, the government not only solidified the JDRF-CIHR Partnership to Defeat Diabetes with a renewed investment of \$15M, matched by JDRF Canada, but a significant amendment was recently made to the Disability Tax Credit, providing equitable access to all Canadians living with T1D.

In addition, **The National Framework for Diabetes Act** (the Act) was passed in June 2021, which required the federal Minister of Health to prepare a report setting out a Framework for diabetes in consultation with relevant stakeholders.

The purpose is to provide policy direction to improve access to diabetes prevention and treatment to ensure better health outcomes for Canadians and identify gaps in current approaches, avoid duplication of effort, and provide an opportunity to report on progress.

As members of the Public Health Agency of Canada’s external advisory group for the Framework, JDRF is confident that our recommendations contribute to the Framework’s key components.





Recommendation 1:



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Funding will also support expansion of a key enabler of the T1D Trial Network, a platform co-designed by patients to engage the T1D community in research, accelerate trial recruitment and collect and report on national T1D data.

The T1D Trial Network

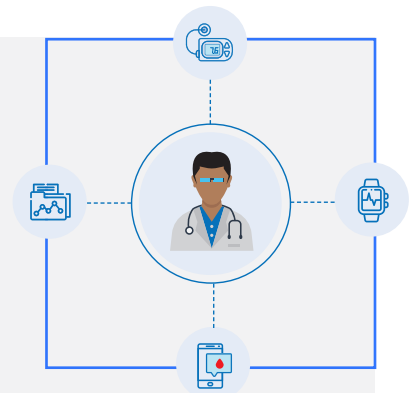
One of the key components of the National Diabetes Framework is to continue to invest and advance research activities which are inclusive of persons with diabetes. Canadian T1D researchers have an exceptional record of leading and participating in high-impact clinical studies and trials and are at the forefront of international research.

Several years prior to establishment of the JDRF-CIHR Partnership to Defeat Diabetes in 2017, the federal government invested in the JDRF Canadian Clinical Trial Network (CCTN), which previously supported practice-changing trials such as the CONCEPTT study of continuous glucose monitor use in pregnant women with T1D, and the first ever trials of stem cell-based therapy for T1D.

However, although the legacy of CCTN provided a foundation for work now supported through the JDRF-CIHR Partnership to Defeat Diabetes, the limited number of clinician researchers in this field, lack of long-term funding, and fragmentation of resources continue to hinder efficient planning and execution of multi-centre trials and translation of research outcomes to the clinic.

JDRF’s global research strategy is focused on driving development and commercialization of therapies to cure T1D or prevent it in people at high risk of the disease. To leverage Canada’s strengths, build Canadian research capacity, and accelerate development of new therapies, we intend to build on the legacy of CCTN and revolutionize a Canadian T1D Trial Network that will drive globally impactful T1D research, and to provide funding to support this network for up to five years.

Additionally, this funding will support up to 7 transformational T1D trials selected based on their potential to improve care and advance curative therapies through rigorously reviewed competitive funding opportunities.



Economic Impact

Each trial supported by the Canadian T1D Trial Network will provide job opportunities for up to 30 clinical and research staff, knowledge mobilization experts, patient partners, and other highly qualified personnel. Network infrastructure will also support a minimum of 8 new, long-term jobs across Canada, for a total of over 200 jobs for highly skilled qualified personnel. In addition, the Network will provide 6-8 dedicated awards to clinicians to allow for protected time for research, building capacity for future T1D trials in Canada and expanding the pipeline of clinical research activity.

The Network will also provide additional exceptional training opportunities for students and postdoctoral fellows working on projects supported by the Network. Once established, the Network has the potential to act as a platform to attract substantial funding from industry to run T1D trials of new therapies or from other funders to support additional trials and ancillary studies and will also open countless avenues for additional research studies that can leverage data generated by Network studies.



A Type 1 Diabetes Registry

Another component that the Framework highlights is data collection. A national T1D registry would accomplish our collective goal of improving national diabetes data, through leveraging current partnerships to scale up and expand existing initiatives.

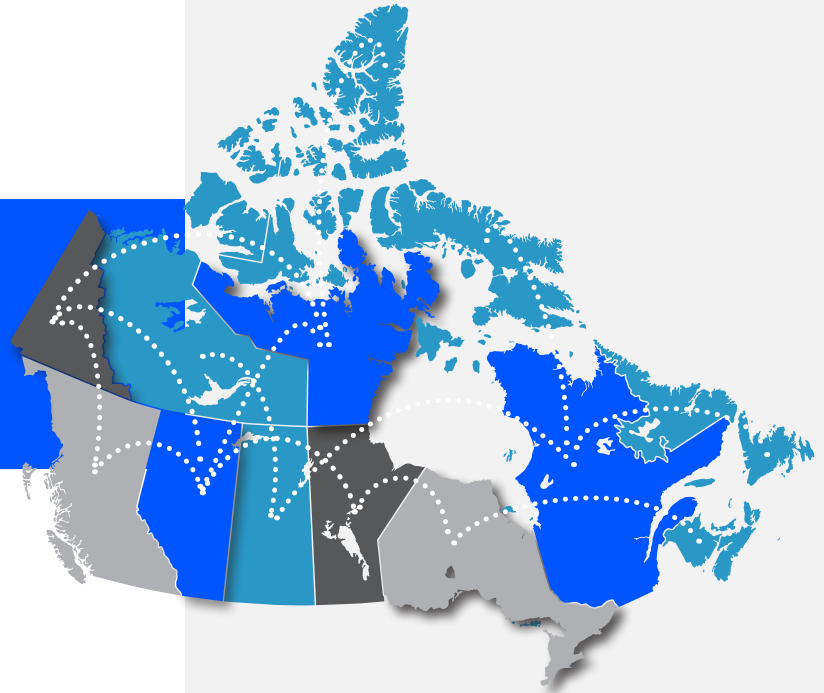
The primary barrier to successful completion of T1D clinical trials is recruitment: up to 80% of JDRF-funded trials are delayed due to slow recruitment, and yet the primary reason people do not participate in trials is because they were simply unaware. Moreover, patient engagement in the research process provides enormous value to researchers and helps to ensure optimum trial execution, knowledge mobilization and governance. To ensure the success of our proposed T1D Trial Network and the individual trials it will support, we intend to partner with researchers to expand and leverage existing Canadian initiatives that have been designed to facilitate T1D community engagement, accelerate trial recruitment and collect T1D data.



There is a need for a dedicated T1D data platform that can be leveraged for research purposes. However, despite the increasing prevalence of diabetes, Canada lacks reliable data about people living with diabetes that can be shared and linked for research purposes.

For example, although good administrative, billing, laboratory and pharmacy data exist, these data are fragmented; inaccessible and difficult to link for research purposes, particularly across provincial boundaries; and even something fundamental, diabetes type, is often not reliably indicated.

Although members of the Canadian PediAtric diabetes Consortium (CAPACity) have developed data registries, these are currently at the centre or provincial level and are limited to data on children with T1D, who represent only ~10% of Canadians with T1D. Similarly, Statistics Canada reports data about T1D and type 2 diabetes (T2D) together, even though the risk factors, pathology, age of onset, management, care and lived experience of these diseases are entirely different.



JDRF-funded initiatives already underway are working to address the need for effective community engagement, trial recruitment and national T1D data to accelerate research, and we could leverage this infrastructure to ensure the success of a Canadian T1D Trial Network.

The patient-oriented approach of these ongoing initiatives means that we are strongly positioned to build a Network that engages and empowers patients and ensures that research goals are aligned with the needs of the T1D community.

Recommendation 2:



The Government of Canada should invest \$5M over 3 years into research focused on novel interventions that address mental health in people with T1D.



The Minister of Health has been mandated to “increase investments in mental health services across all provinces and territories.” Due to the heavy burden of self-management and other factors such as social stigma, people living with T1D are more likely to experience mental health challenges than their peers without T1D including distress, depression, anxiety, eating disorders and suicidal ideation.

The National Diabetes Framework also states that diabetes prevention, management, treatment and care are most effective when approached holistically, taking into consideration people’s physical, social, emotional, mental, spiritual and cultural well-being. This person-centered approach is integral to the Framework’s implementation.



Although mental health disorders are associated with worse health outcomes and even early death in people with T1D, they typically receive less attention than better-known diabetes complications. As we emerge from the COVID-19 global pandemic when mental health is more fragile than ever, there is no better time to tackle this issue by increasing knowledge about interventions that can prevent and treat mental health disorders in people with T1D. However, there are currently many gaps in knowledge, the healthcare system, and community support that mean this critical aspect of diabetes management is often overlooked.



In March 2022, JDRF and Brain Canada announced the results of the first ever Canadian research funding opportunity focused on the area of mental health and T1D. Three different research teams were funded to develop and test different interventions designed to prevent or treat mental health challenges in children, youth or young adults, applying approaches such as cognitive behavioural therapy or positive psychology that can be delivered digitally. Through these trials, hundreds of young people with T1D will gain access to new mental health supports in development. These initiatives are an important but small step forward in a vastly under-researched area.

As JDRF partners with other organizations to make an impact on mental health for people with T1D, a generation of new evidence in the Canadian context will be crucial, particularly in knowledge implementation. Clinical and health systems research is urgently needed to develop and test the implementation of solutions to prevent and treat mental health in people with T1D, particularly in vulnerable populations.

\$5M of new funding for research on mental health and T1D will enable up to 3 large-scale clinical studies focused on testing approaches to prevent or treat mental health disorders in vulnerable people with T1D.



Economic Impact

The trials enabled by this funding will provide new job and training opportunities for up to 90 highly skilled research staff and students. In addition, the interventions tested through these trials, if successful, have the potential to improve the quality of life of hundreds of youth or adults living with T1D who participate in the trials, thereby increasing their productivity at work or school. Finally, the research supported by this funding may even lead to changes in the health system that result in more efficient and effective care for people living with T1D.

Collectively, these efforts will improve and extend lives for people with T1D, build Canadian clinical trial capacity, attract follow-on funding, and create jobs and training opportunities for highly qualified personnel.

