



## Working Towards Transformative Changes in the Organ Donation and Transplantation System

2021-2022 Organ Donation and Transplantation Collaborative Progress Report

### Executive Summary

Committed to improving Canada's performance in organ donation and transplantation (ODT), the Organ Donation and Transplantation Collaborative (ODTC or the Collaborative) was established in 2018 by Health Canada, provincial and territorial health officials (except Québec), Canadian Blood Services (CBS), patients and families, clinicians, and researchers across Canada. Since its inception, ODTC members have remained steadfast in converging their efforts toward the ODTC's vision to achieve ODT system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations.

The 2021-2022 ODTC Progress Report, "*Working Towards Transformative Changes in the Organ Donation and Transplantation System*", highlights significant progress achieved over the last year, with a focus on three foundational priorities – *a pan-Canadian ODT governance system, data for analytics and reporting, and interprovincial organ sharing.*

First, the Collaborative has made significant progress towards a **model for pan-Canadian ODT system governance** that will identify decision-making and accountability mechanisms for ensuring timely, effective and equitable access to ODT services across the country. The University of Ottawa Centre for Health Law, Policy and Ethics has submitted the "*Report II: The Future of ODT System Governance in Canada – Framework and Considerations*" that provided guidance. A preliminary governance model has been developed with draft terms of reference for a federal/provincial/territorial group oversight committee, the design of stakeholder and patient advisory committees, a transparent membership selection process and a mandate for secretariat roles to ensure the coordination of the work. Discussions are still underway to finalize the governance model that will be submitted to the Federal, Provincial, Territorial Conference of Deputy Ministers of Health (FPT CDM) in 2022-2023 for endorsement.

Funded by Health Canada, the Canadian Institute for Health Information (CIHI) and Canada Health Infoway (Infoway) are co-leading the multi-year **Pan-Canadian ODT Data and Performance Reporting System** project, which has taken great strides this year thanks to the collaboration of representatives across the ODTC including the provincial and territorial Ministries of Health. As demonstrated by research, a high performing ODT system relies on comprehensive, standardized and timely data to inform decision making, guide practice, identify improvement areas for preventing missed organ opportunities, increase potential and actual donated donor volumes, and optimize organ utilization for transplantation. Similarly, high quality data can inform ODT systems about patient experience and outcomes for transplant recipients and living donors.

In June 2021, the FPT CDM confirmed its support for the project and its related activities over the next three years. This support has allowed CIHI, Infoway and their partners to initiate and substantially advance a set of priority initiatives. Some key highlights include:

- A multi-jurisdictional procurement exercise to supply deceased donor management (DDM) software, replacing paper records and use of old technology such as fax machines to transmit time sensitive information.
- A shared integration hub to achieve system interoperability of existing DDM software used by British Columbia, Ontario and Quebec to support out-of-province donor offers and to transmit data to CIHI and CBS.
- An extensive stakeholder engagement process to prioritize pan-Canadian indicators and measures for the new ODT performance reporting tool.
- The development of pan-Canadian data standards and minimum data sets for deceased donation, living donation and transplantation and publish technical specification for vendors.

A higher performing ODT system also relies on an improved organ sharing processes that will enhance the effectiveness of the ODT system by increasing the number of quality transplants across the country and providing better options to a greater number of patients. To this end, the Collaborative developed recommendations on **interprovincial organ sharing (IPOS)** with the objective of maximizing organ sharing and ensuring equity and quality transplantation across Canada. Recommendations were endorsed by the ODTC Coordination Committee.

Aligned with the ODTC vision, members have remained tirelessly involved **in innovative initiatives, funded by Health Canada, with the aim of strengthening a higher-performing ODT system and improving equity in living and deceased donation and transplantation areas.** One of the common threads running through all projects is to reduce missed organ opportunities through new practices and cutting-edge approaches, including artificial intelligence-related projects and evidence-based recommendations that will inform programs and policies. Results stemming from these projects will be disseminated in 2022-2023.

Needless to say, all this work would not have been possible without the tremendous contribution of patient and family representatives who are instrumental in informing, deepening members' perspectives and providing advice. Based on their lived experience, their far-reaching contributions help address gaps along the ODT journey in a sustainable way.

Next year will be a turning point because projects will be completed and we will prepare for the transition to a new ODT governance structure post-ODTC.