

# The Pan-Canadian Organ Donation and Transplantation Data System Project: Leveraging Lessons Learned from NephroCAGE

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**2023 International NephroCAGE Symposium**








# Outline



1. Organ donation and transplantation in Canada
2. CIHI and Canada Health Infoway
3. Canadian Organ Replacement Register (CORR)
4. The Pan-Canadian Organ Donation and Transplantation (ODT) Data and Reporting System: Overview
5. Project workstreams
  - Indicators and measures
  - Standards and repository
  - Digital solutions
  - Reporting and data access
6. Leveraging lessons from NephroCAGE

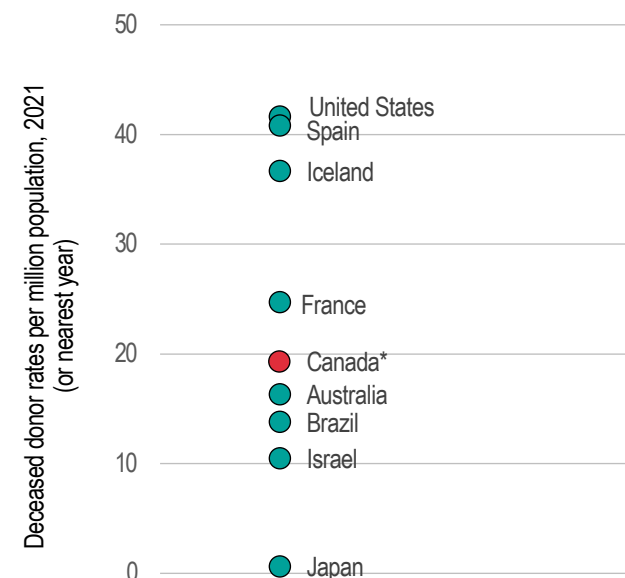
# Despite significant investments and improvements in organ donation and transplantation (ODT) practices, Canada is not meeting the need for organ transplants

- In 2022, over 3,777 Canadians were waiting for an organ transplant; 270 people died while waiting.
- There are significant variations in donation rates and access to transplantation across jurisdictions
- Information gaps: missed donation opportunities; organ utilization; detailed wait-list information (including removals); impact of emerging practices; long-term transplant recipient and living donor outcomes

Across Canada in 2022		
Organ	Number of organs transplanted in 2022	Number of patients on wait-list on Dec 31, 2022
Kidney 	1,795	2,813
Liver 	594	517
Lung 	352	210
Heart 	153	133
Pancreas 	94	171
<b>Total</b>	<b>2,936</b>	<b>3,777</b>

**Source**  
Canadian Institute for Health Information. Summary Statistics on Organ Transplants, Wait-Lists and Donors, 2022. Ottawa, ON: CIHI; 2023.

Worldwide actual deceased organ donors rate 2021



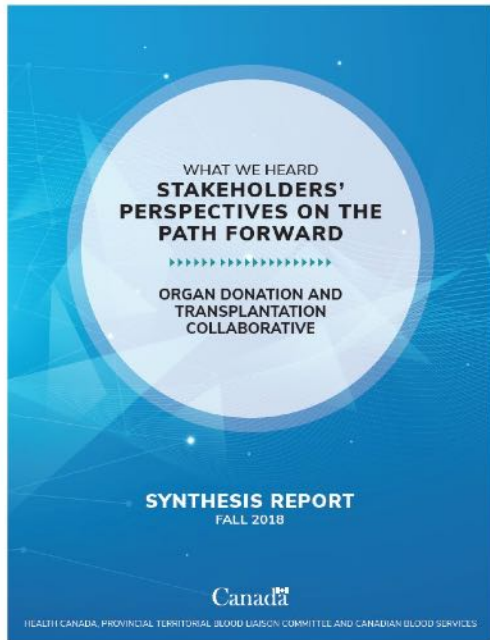
**Note**

\* Actual donor rate = utilized donor rate

**Source**

Global Observatory on Donation and Transplantation, 2021.

# In 2018, the Federal Government recognized an opportunity to drive transformation across Canada in the ODT space



“The lack of a pan-Canadian data repository and system performance indicators is the **Achilles heel** of the pan-Canadian Organ Donation and Transplantation (ODT) system”.



- The Organ Donation & Transplantation Collaborative’s 2018 synthesis report led to the initiation of this project.
- The Federal Government, through Budget 2019, invested **\$40.4 million over 5 years (with \$5 million/year ongoing)** in the development of a pan-Canadian data and performance system for ODT, in collaboration with provincial and territorial partners.
- **CIHI and Infoway** were given a mandate by Health Canada **to partner on the national initiative** and collaborate with all jurisdictions and the ODT community.

# About CIHI: mandate, vision and values



## About CIHI

● The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization that provides essential information on Canada's health systems and the health of people living in Canada.

### ● **Mandate**

Deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care.

### ● **Vision**

Better data.  
Better decisions.  
Healthier Canadians.

### ● **Values**

- Inclusion
- Integrity
- Collaboration
- Excellence
- Innovation

# CIHI hosts extensive linkable, pan-Canadian data across the health care continuum...



## Types of care

- Hospital and emergency
- Mental health
- Home care
- Long-term care
- Rehabilitation
- Pharmaceuticals
- Clinical registries: organ transplant/renal, hip and knee replacements; trauma
- More



## Patient-reported data

- Patient-reported outcome measures (PROMs)
- Patient-reported experience measures (PREMs)



## Health spending

- Patient costing data
- Hospital and regional health authority financial accounts
- Physician billing
- System-wide health expenditures



## Health workforce

- Physicians
- Nurses
- Occupational therapists
- Pharmacists
- Physiotherapists
- Allied health professionals
- More

# About Canada Health Infoway

- At Canada Health Infoway (Infoway) we believe a more connected and collaborative system is a healthier system, and we work with governments, health care organizations, clinicians and patients to make health care more digital
- We're working to ensure that everyone is able to access their personal health information, book appointments, get prescriptions, view lab test results and access other health services, online
- We're working with our partners to transform the health system because we know that digital in health can be as transformative as digital has been in other aspects of our lives
- We're an independent, not-for-profit organization funded by the federal government.

Visit us online at [www.infoway-inforoute.ca](http://www.infoway-inforoute.ca)

# CORR: Canadian Organ Replacement Register

- Pan-Canadian; existing since 1972
- The CORR Board represents the dialysis/transplant communities and advises CIHI
- Multiple data collection streams: dialysis, deceased donation, living donation, & transplantation
- CORR is longitudinal and patient-oriented
- CORR follows patients across provincial boundaries
- Organ donors and recipients are linked by each transplanted organ
- CORR can be linked across other CIHI databases





# Vision for the Pan-Canadian ODT Data and Performance Reporting System

**A world-leading data-driven ODT system — informed by high-quality and timely information — that optimizes access, efficiency, quality and outcomes throughout the continuum of care for the benefit of patients, donors and families across Canada**

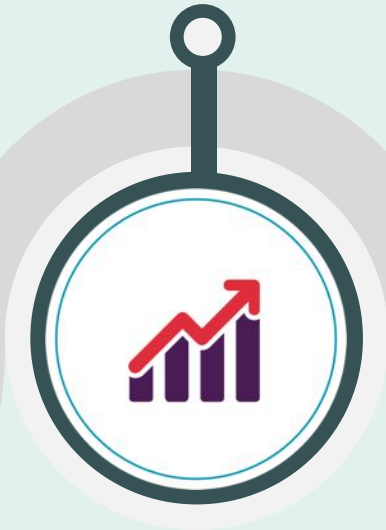
Project deliverables	Intermediate outcomes	Long-term outcomes
<ul style="list-style-type: none"> <li>• Indicators and measures</li> <li>• Data standards and minimum data sets (MDS)</li> <li>• Digital solutions</li> <li>• Pan-Canadian data repository</li> <li>• Performance reporting and data access</li> </ul> <p><b>Access to high-quality, timely data to</b></p> <ul style="list-style-type: none"> <li>• Measure ODT performance across Canada</li> <li>• Provide system transparency</li> <li>• Stimulate research and innovation</li> </ul>	<ul style="list-style-type: none"> <li>• ↑ donor volumes</li> <li>• ↓ missed donation opportunities</li> <li>• ↑ organ utilization</li> <li>• ↑ access to transplantation</li> <li>• ↓ wait times</li> <li>• Improved outcomes for transplant recipients</li> <li>• Improved outcomes for living donors</li> <li>• ↓ variations across jurisdictions</li> <li>• ↑ efficiency in care and cost savings</li> </ul>	<ul style="list-style-type: none"> <li>• Timely and equitable access to quality transplantation</li> <li>• Organ supply meets organ demand</li> <li>• Successful transplantations that last a lifetime</li> <li>• Health system cost savings</li> </ul>

# What will this project achieve?

**Pan-Canadian ODT indicators and measures for health system performance reporting**

**Digital solutions and integrations to support the work of system operators**

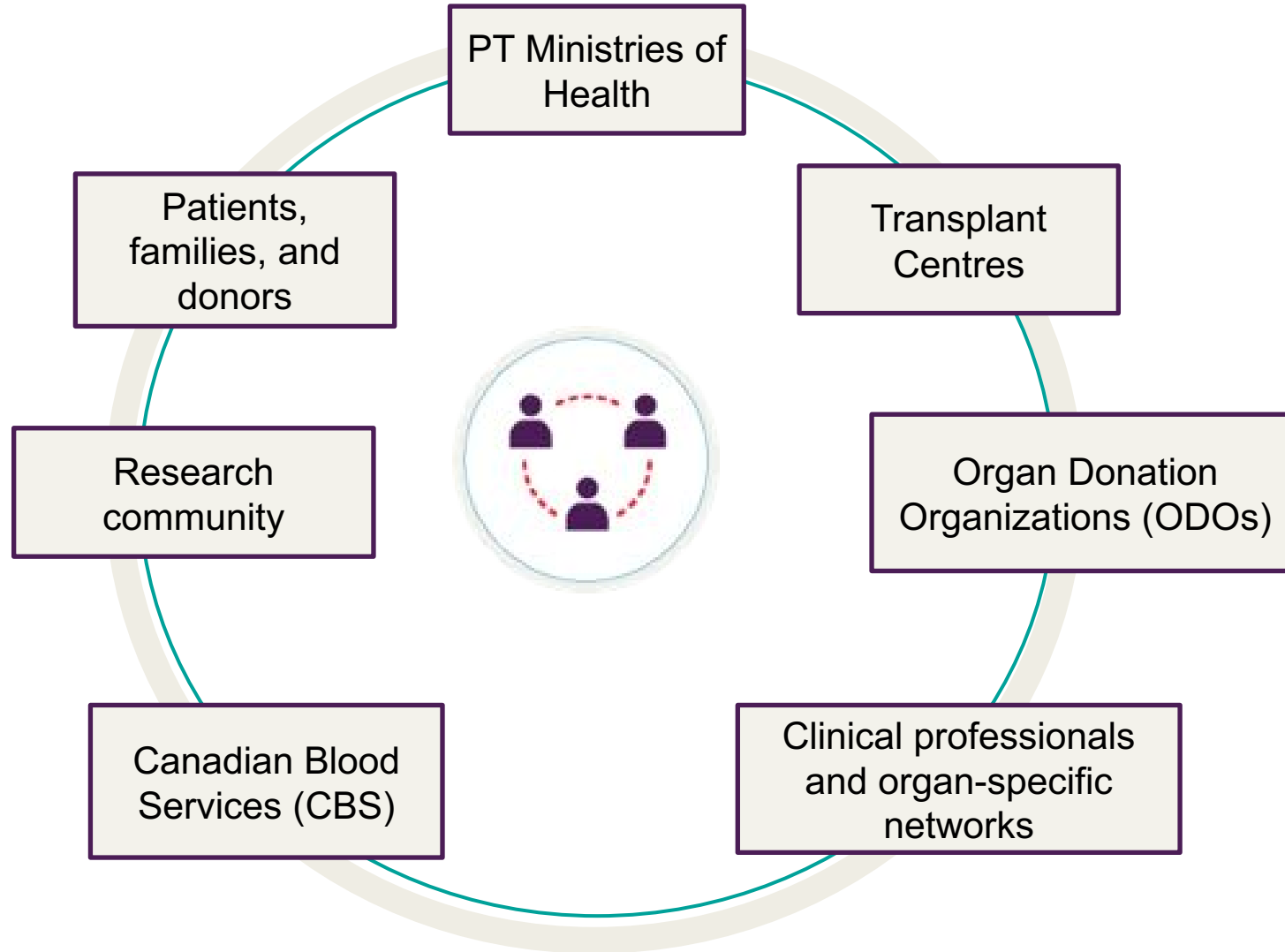
**Timely secure and public performance reporting and data access**



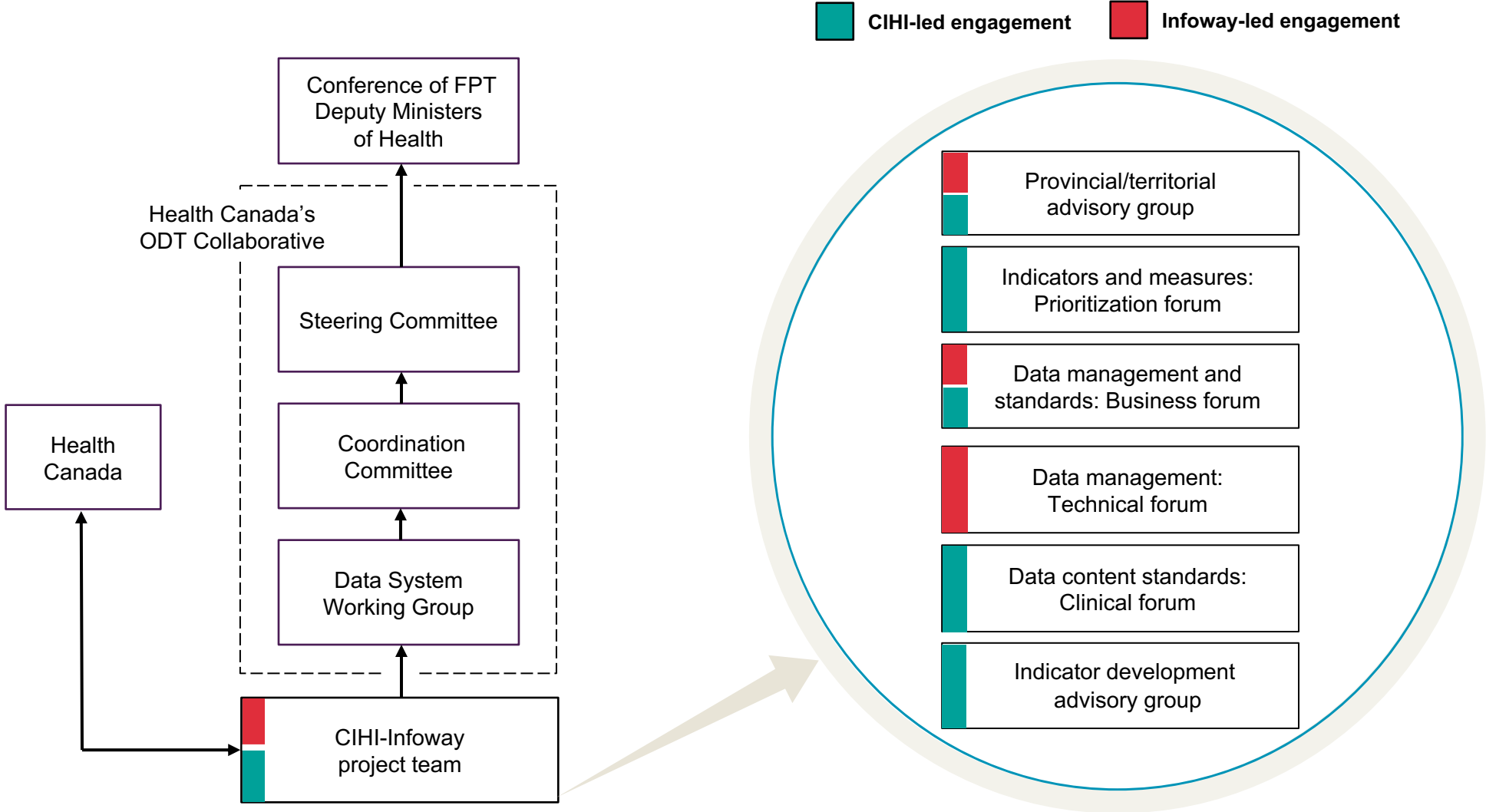
**Minimum data sets and data standards to support data collection**

**Creation of a pan-Canadian ODT data repository (CanODT)**

# Extensive engagement with the ODT community across Canada



# Project governance and expert advisory forums



# Project achievements to date



## Indicators and measures

- Extensive engagement for indicator prioritization process complete, released summary on [cihi.ca/odt](https://cihi.ca/odt)
- Indicator Methodology Development for first release completed with support of Advisory Group



## Data standards

- Developed national data standards for DD, TX, LD to build into digital solutions available on [cihi.ca/odt](https://cihi.ca/odt)
- MDS include coding to support interoperability and indicators



## Digital solutions

- Integration Hub Phase 1 complete to digitally connect 3 ODOs for information sharing
- Deceased Donation Management Digital solution procured to modernize the way organ donation data is collected and managed
- Transplantation and Living Donation Management Digital Solution procured to modernize the way living donor and transplant recipient data is collected



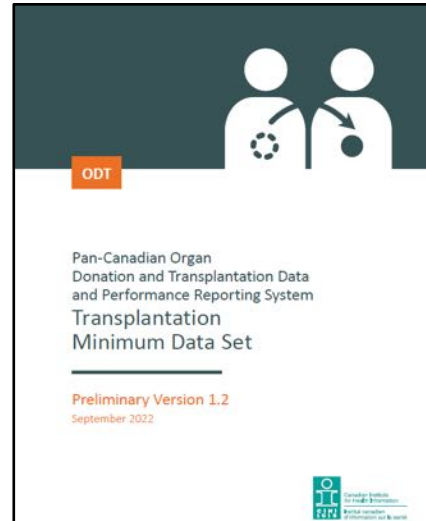
## Data repository

- Development of CIHI data repository solution in progress, with aim to be open for business in Fall 2023 for DD data
- Released DD vendor submission package
- Initiated work on data repository updates for Tx; LD to follow



## Reporting and data access

- Developed requirements and determined initial list of indicators for first ODT public reporting release on cihi.ca by March 2024
- Collaborating with patient/family partners to plan and execute focus group sessions for input on data visualizations for ODT public reporting



**New CIHI ODT data repository planned to be ready to receive deceased donation data in Fall 2023**

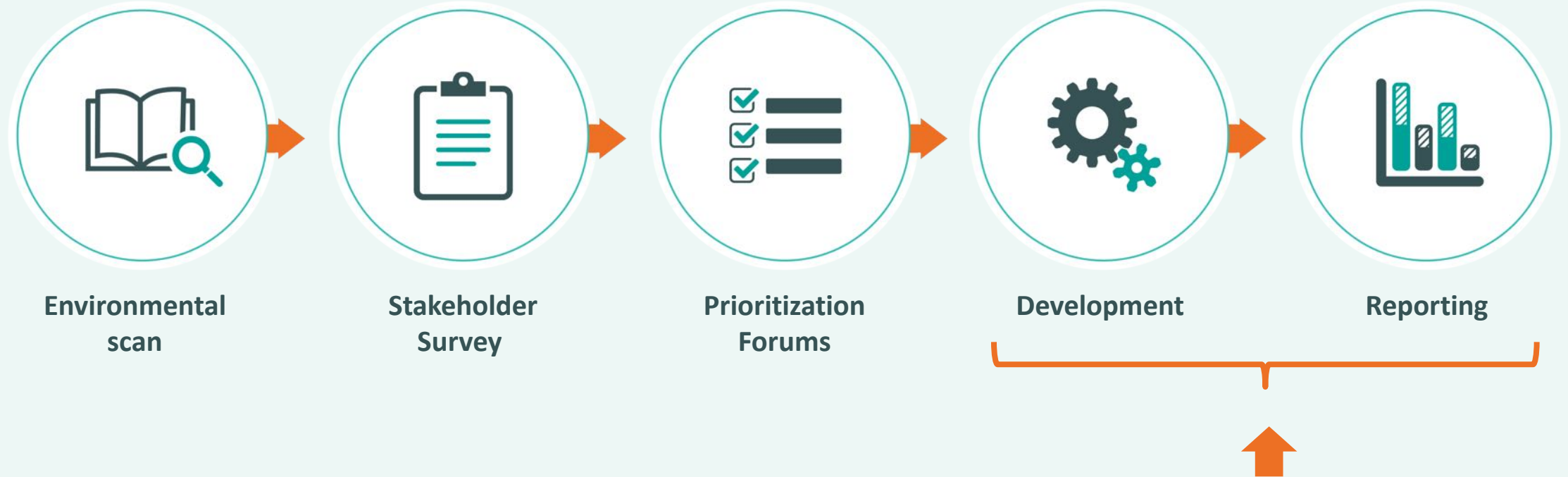
As July 2023

DD=deceased donation LD=living donation Tx=transplantation



# Indicators and Measures

# ODT indicators & measures development process



Environmental  
scan

Stakeholder  
Survey

Prioritization  
Forums

Development

Reporting

**Prioritization complete;  
Indicator work has shifted to development and reporting**

# Available now! Pan-Canadian ODT Prioritized Indicators Report



## Pan-Canadian Organ Donation and Transplantation Prioritized Indicators

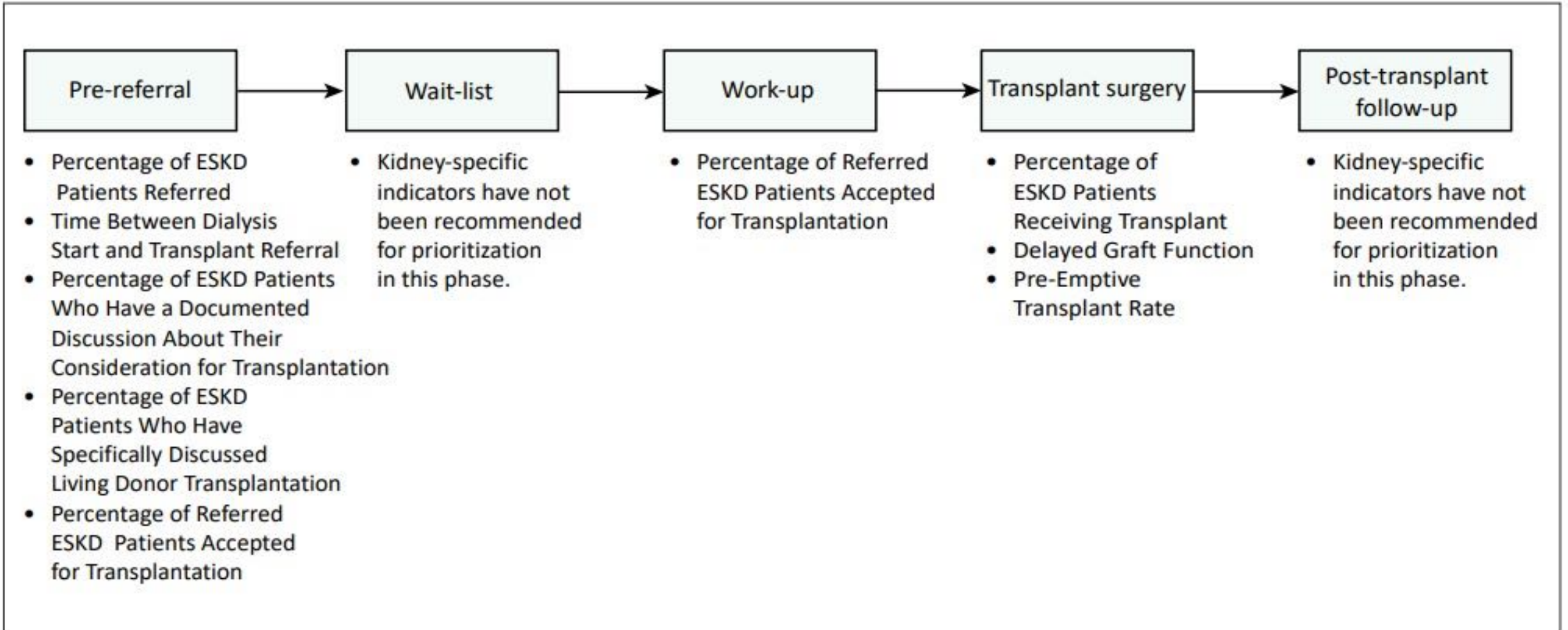
March 2023



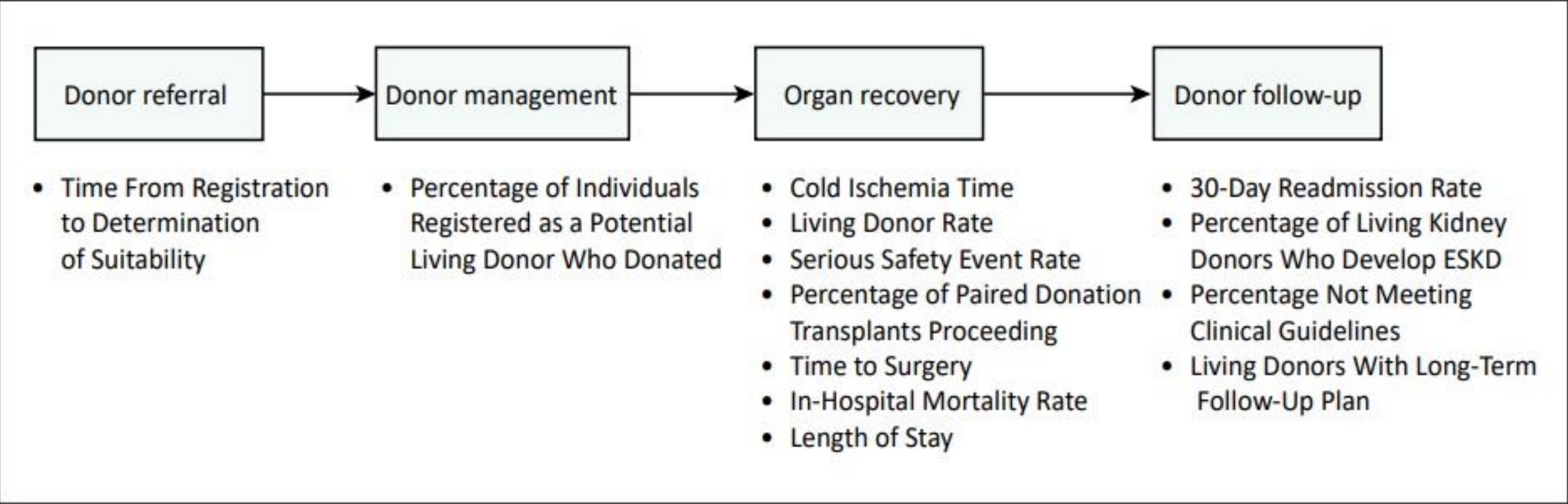
- Report summarizes results of extensive indicator prioritization sessions (12 in total) that resulted in 78 indicators covering 10 ODT clinical areas
- Acknowledging and thanking the significant contributions and input from members of the ODT community
- Finalized **Report** available on [cihi.ca/odt](https://cihi.ca/odt)



# Prioritized kidney transplantation indicators by workflow phase



# Prioritized living donation indicators by workflow phase

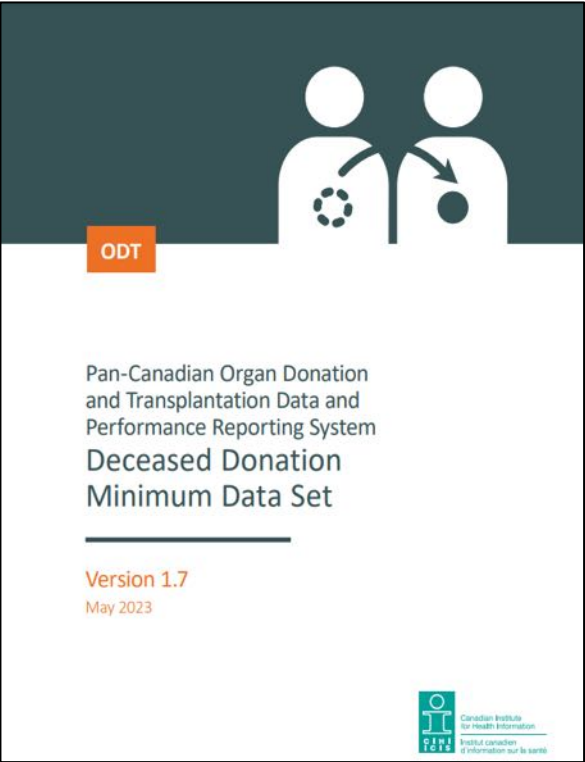




# Standards and Repository

# CIHI pan-Canadian ODT minimum datasets (MDS) on [www.cihi.ca/odt](http://www.cihi.ca/odt)

## Deceased Donation




ODT

Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System  
Deceased Donation  
Minimum Data Set

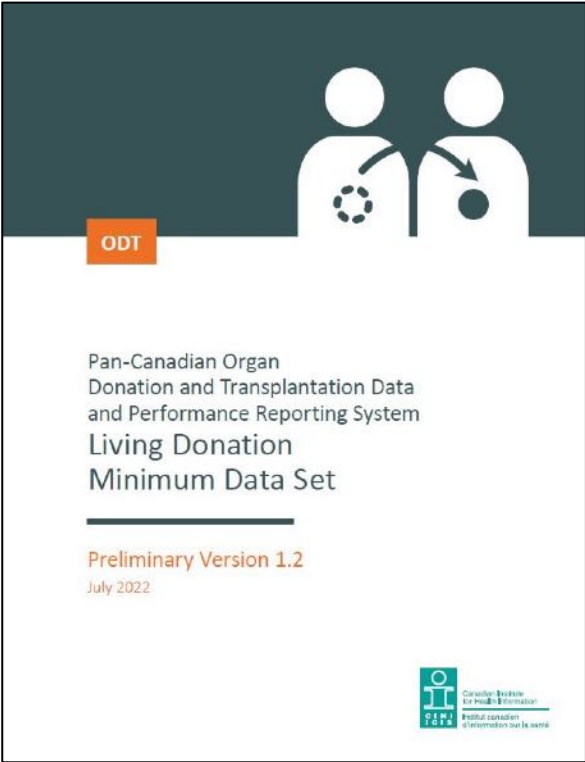
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Version 1.7  
May 2023



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## Living Donation




ODT

Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System  
Living Donation  
Minimum Data Set

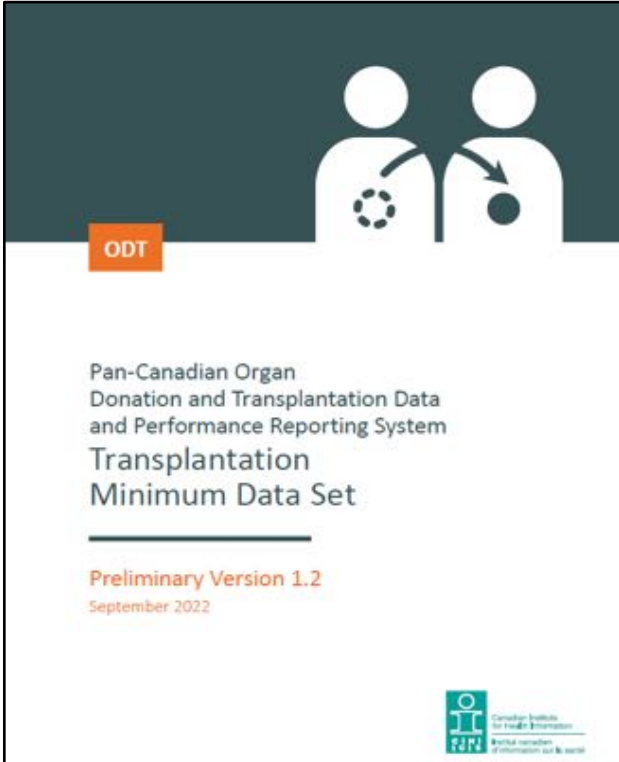
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Preliminary Version 1.2  
July 2022



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Institut canadien d'information sur la santé

## Transplantation




ODT

Pan-Canadian Organ Donation and Transplantation Data and Performance Reporting System  
Transplantation  
Minimum Data Set

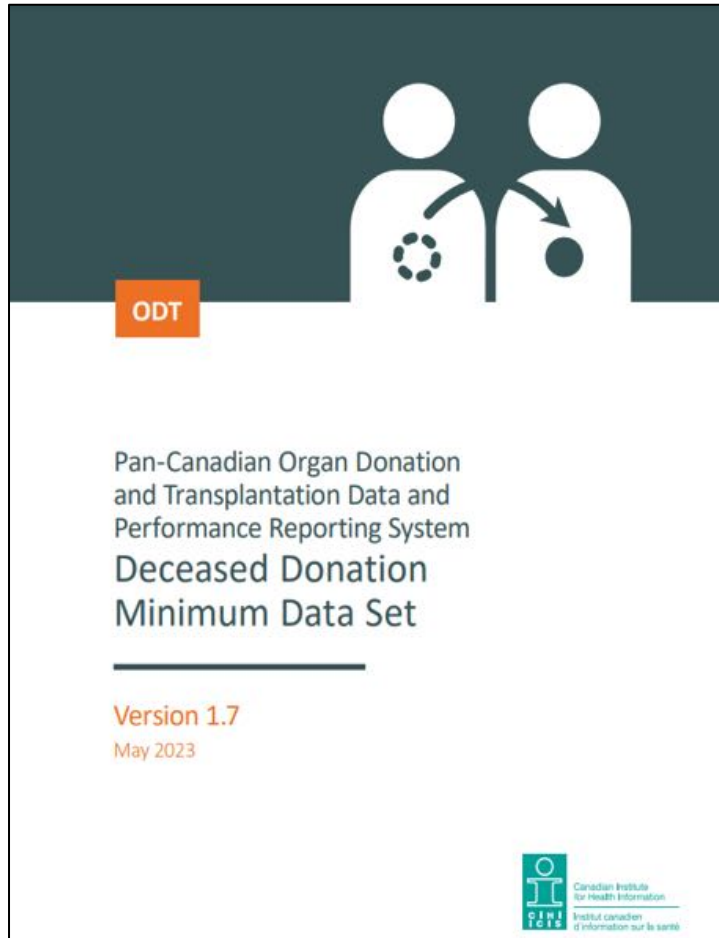
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Preliminary Version 1.2  
September 2022



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# Improving interoperability of ODT data standards

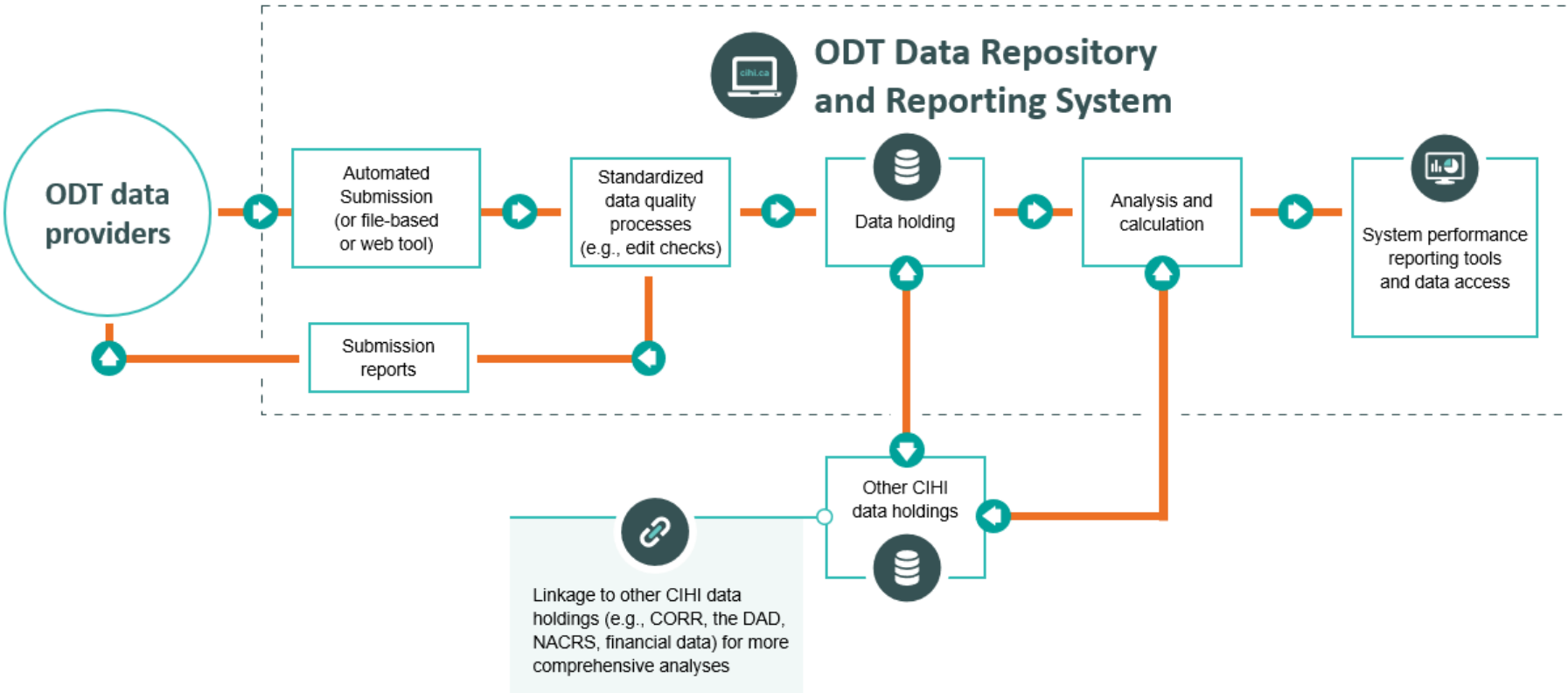





Data element name	Valid values
Consented Donor Organ Disposition	<ul style="list-style-type: none"><li>• 37401000087100: Organ donation for transplant</li><li>• 37391000087103: Organ donation for research</li><li>• 37381000087100: Organ donation for medical education</li></ul> <p><b>Note:</b> The value set codes are sourced from SNOMED CT Canadian Edition.</p>


Majority of the coding for ODT value sets were sourced from established standards including:

- International Organization for Standardization (ISO)
- Health Level Seven (HL7)
- Logical Observation Identifiers Names and Codes (LOINC)
- **Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) Canadian Edition** (managed by Infoway)
  - **DD MDS** – 89 new concepts & descriptions created
  - **Tx/LD MDS** – 76 new concepts & descriptions created

# Data flow for CanODT



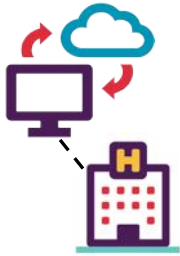
-  Stakeholder input regarding MDS and API integration
-  Requirements, architecture, specs and build (phased release)
-  Technical submission packages for vendors

 New CIHI ODT data repository ready to start receiving data by **Fall 2023 (deceased donation)**



# Digital Solutions

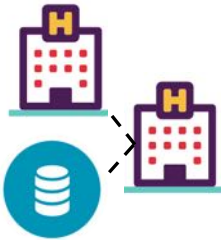
# Advancing Interoperability in ODT Systems Across Canada



## 1. Deploying Technology Solutions

Procure and implement modernized, commercial off-the-shelf data management solutions to Organ Donation Organizations and Transplant Centres

Support high quality care and improved information sharing across provinces, instead of relying on outdated systems, paper, email, fax and phone



## 2. Integrating Systems

Integrate existing and newly deployed data management solutions to relevant end points

Reduce duplicate data entry, potential for human error in transcribing data, system inefficiencies, fragmented workflows



## 3. Standardizing Data

Establish common Minimum Data Set (MDS) and data standards (e.g., SNOMED-CT)

Enable the comparability of the data locally, provincially, and nationally through standardized clinical vocabularies and exchange standards



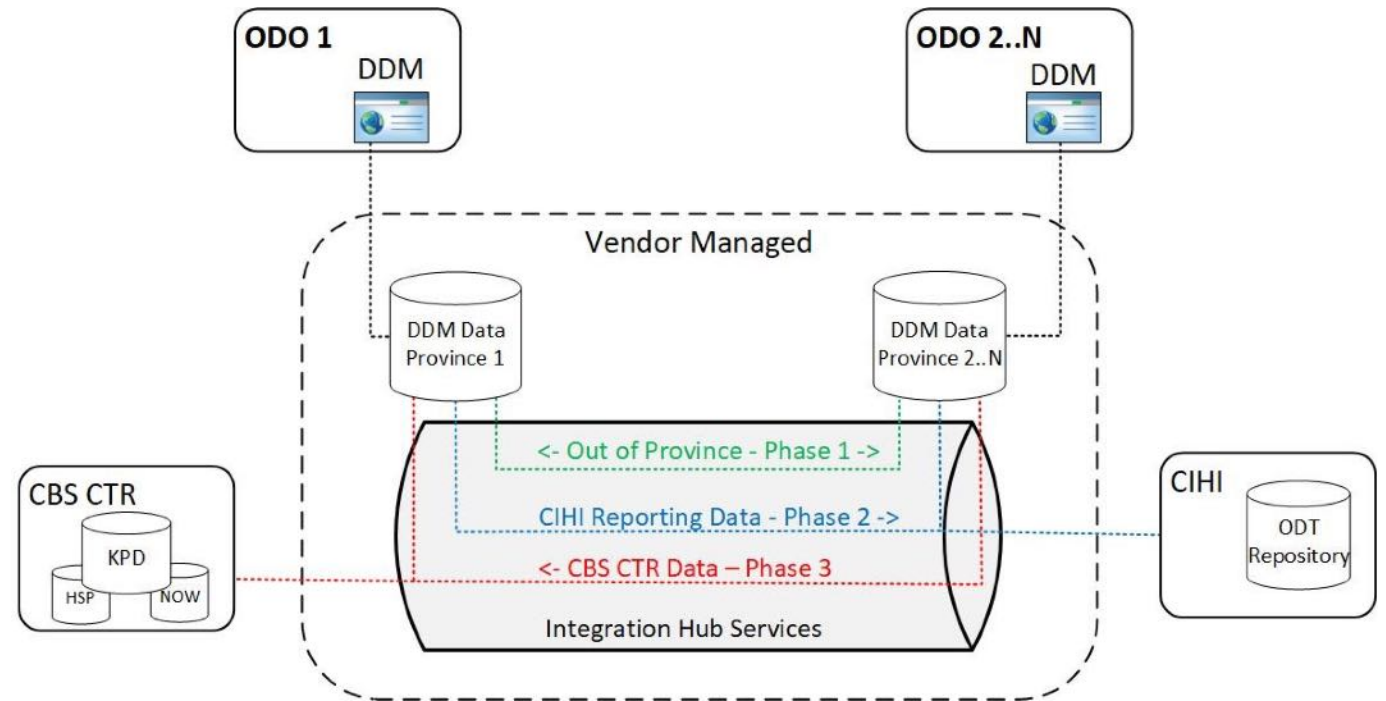
# Deceased Donation Management (DDM)

## 1. Solution Procurement/ Deployment

- Seven of ten provinces in Canada participated in a multi-jurisdictional procurement process in 2021
- Consensus regarding solution requirements was achieved through a 4-month process involving representatives from all participating provinces
- iTransplant™ was identified as the preferred vendor; planning is now underway for solution deployment
- When complete, iTransplant™ will be operational in all provinces across Canada

## 2. Integration of Solutions

- Our project is supporting the development of an “Integration Hub” to support the secure digital transfer of data among multiple key systems
- Three phases:
  1. Interprovincial integration to support organ offers
  2. Data submission to CIHI
  3. Data submission to the Canadian Transplant Registry (CTR) at Canadian Blood Services (CBS)



# Transplantation and Living Donation Management (TLDM)

## 1. Solution Procurement/Deployment

- There is a very heterogeneous mix of technical environments across the 29 transplantation centres in Canada – variations in level of modernization, integration, vendor products
- Similar to DDM, consensus regarding solution requirements was achieved through a process involving representatives from all participating provinces
- Afflo (Transplant Advancement Inc.) was identified as the preferred vendor through a multijurisdictional procurement process; planning will begin for solution deployment to select transplantation programs

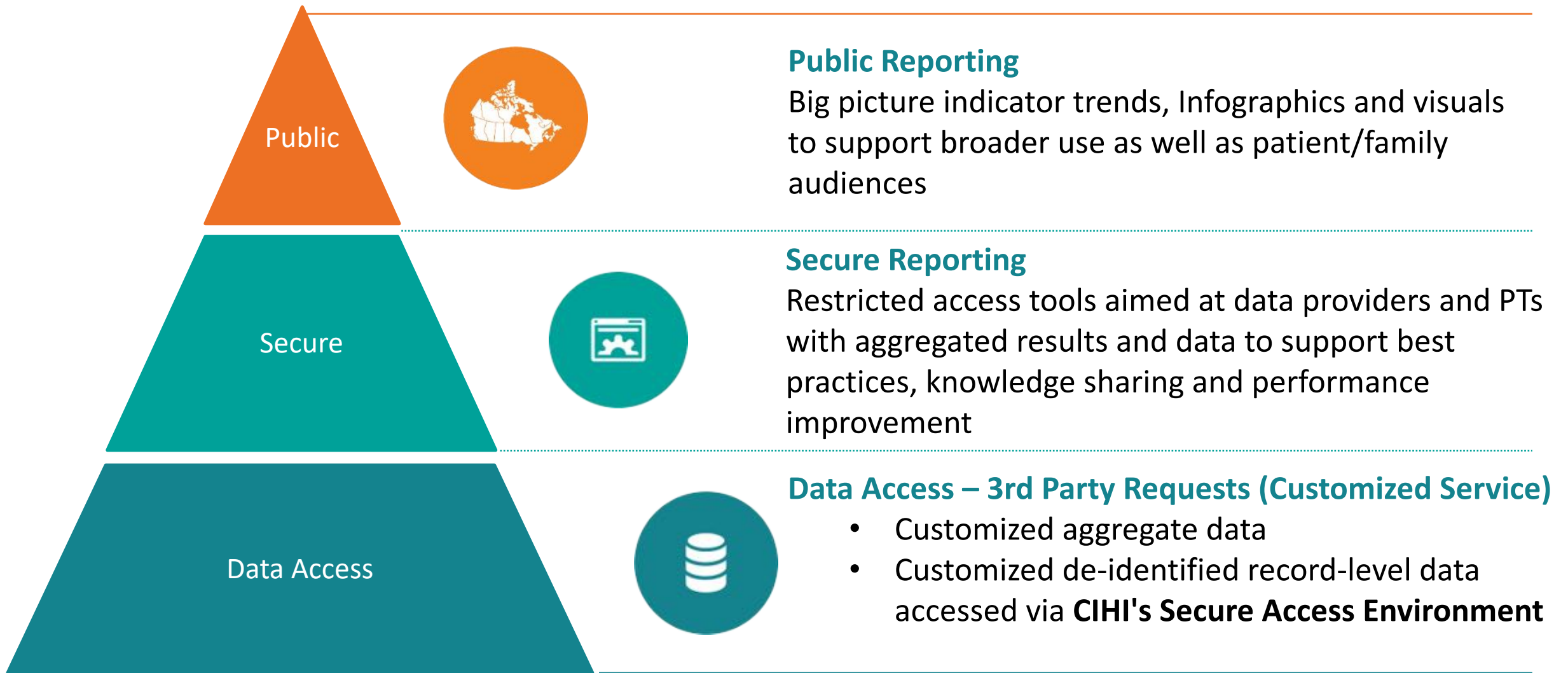
## 2. Integration of Solutions

- All sites will be integrated to the CIHI ODT data repository
- Other integrations (e.g. Hospital Information System, HLA lab) will be considered on a case-by-case basis
- Due to variations in solution vendors and technical infrastructure across transplant centres, integration of sites is being largely custom-designed for each vendor/province
- Where possible (e.g. different sites with same vendor solution), common integration models will be leveraged
- Our first integration pilot projects, which will integrate Cerner and EPIC-based transplantation centres to the CIHI ODT repository, is in planning phase



# Reporting and Data Access

# ODT health system performance reporting & access



# Leveraging Lessons from NephroCAGE

- Collaborative efforts to create new knowledge and data-driven insights will accelerate learning and clinical application
- Distributed data networks will be the gold standard for leveraging the power of data that are housed in disparate sites/locations
- Federated learning on distributed data networks will increase the power and efficiency of developing, testing, validating, and deploying predictive analytic tools in the clinical setting
- Appropriate attention to impact analyses are needed to understand how prediction models can improve the delivery and outcomes of care



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**Canada Health Infoway**



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