

# DATA COLLECTION & PUBLIC REPORTING

CONTENT: MAY 2022

## INTRODUCTION

### DATA COLLECTION AND PUBLIC REPORTING ARE EVIDENCE-BASED BEST PRACTICES

In 2021, The International Donation and Transplantation Legislative and Policy Forum, hosted by Transplant Québec and co-hosted by the Canadian Donation and Transplantation Research Program (CDTRP), assembled international experts in the fields of donation and transplantation to provide expert guidance on the structure of an ideal organ and tissue donation and transplantation (OTDT) system.

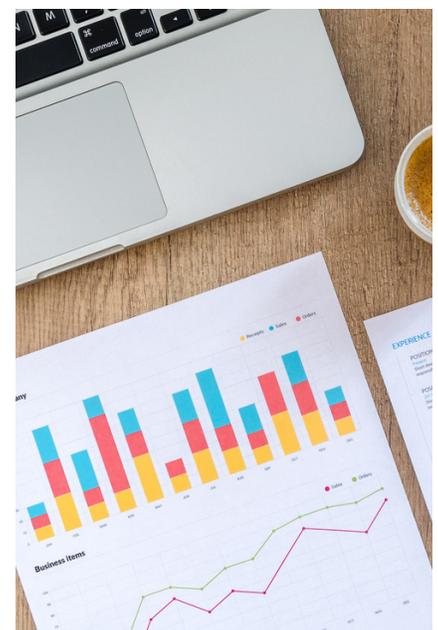
The Forum concluded that legislation should require OTDT systems to operate transparently by publicly reporting system performance metrics. Timely and standardized data collection drives further system improvements by allowing an understanding of opportunities and challenges in an organ donation organization (ODO) and the system as a whole.

Data collection and public reporting are key evidence-based best practices among global deceased organ and tissue donation and transplantation leaders.

### WHAT IS DATA COLLECTION AND PUBLIC REPORTING IN OTDT SYSTEMS?

Data collection, analysis, and public reporting are pillars of an open and transparent OTDT system. Data drives improvements in OTDT practices by informing policy, improving patient care, creating accountability structures, and increasing scientific knowledge [1].

It is crucial to collect data to monitor and improve OTDT systems and to maintain transparency.



## Data that ODOs should collect include, but is not limited to, the below list

### REGISTRY METRICS

- Organ donation registrations

### WAITLIST METRICS

- Non-identifying information of those on a waitlist, including age, blood type, gender, and diagnosis
- Number of people waiting for transplants of different organs
- Number of people with organ failure but not on a transplant waitlist
- Number of people who died waiting for a transplant
- Waitlist times

### DONATION METRICS

- Non-identifying information of deceased donors, including age, ethnicity, gender, and circumstances of death (donation after circulatory death, donation after neurological determination of death)
- Identification and referral rates of patients who are potential donors to the ODO
- Compliance with deceased donation pathways
- Consent rate among families approached for deceased donation
- Number of donated organs (living and deceased)
- Number of organs recovered per deceased donor

### TRANSPLANT METRICS

- Number of transplants performed by organ type
- Recipients of organs, including age, ethnicity, gender, and diagnoses
- Transplantation outcomes



Some or all of these data should be available for public reporting. Public reporting of system performances, when combined with other public awareness activities, supports organ donation awareness and education, builds trust in OTDT systems, and prevents misinformation [5]. ODOs and other agencies must, however, maintain donor and recipient privacy in data collection and reporting [2].

# BENEFITS OF DATA COLLECTION AND PUBLIC REPORTING

OTDT systems are dependent on public trust. Donations and transplantation activities must operate fairly and openly to maintain that trust. The World Health Organization's Guiding Principles state that "The organization and execution of donation and transplantation activities, as well as their clinical results, must be transparent and open to scrutiny, while ensuring that the personal anonymity and privacy of donors and recipients are always protected" [6]. The only means to comply with this obligation of transparency is to collect and report data.

Besides fulfilling obligations towards transparency, timely, accurate data is essential in identifying opportunities and challenges in the donation and transplantation process [7,8]. In jurisdictions with mandatory referral policies, retrospective auditing of death records provides data on compliance and missed donor opportunities (i.e., a clinician does not refer a potential donor or refers too late) [9,10,11]. In Spain, continuous reviews of its death records are a key element of their OTDT system [8].

Data collection and analysis allow for regular feedback to hospitals, clinicians, and administrators. In addition, ODO decision-makers can learn and support adherence to best practices in hospitals when referral outcome data is connected to other related performance measurements [9].

ODOs can implement strategies to optimize their system performance by identifying areas where potential donors are missed [12]. For patients and their families, access to data and information supports informed decision-making [13]. In addition, collecting more granular data may be beneficial in monitoring equity and fairness in allocation policy [14].

In Europe, experts developed a roadmap to improve access to transplantation and post-transplant outcomes, given the significant variability in performance indicators among European countries. The roadmap concluded that it is essential to have a continuous assessment with external audits, ongoing comparison of ODO efficiency with peer programs, and transparency of hospitals by reporting their performance [15].

There is broad consensus that improved data collection supports improved ODO performance and ultimately leads to more lives saved [16].



# CHALLENGES WITH DATA COLLECTION & PUBLIC REPORTING

Data collection allows the comparison of donation and transplantation activity between ODOs and jurisdictions. Comparisons support innovation, better policy, and learning from best practices. However, challenges exist in collecting and standardizing this data.

For example, issues persist around a lack of agreement on which specific metrics ODOs should collect and the precise definitions of those metrics [1]. Worldwide, ODOs do not have a standard procedure to define potential donors and determine the true potential for deceased donation [12]. In Canada, provinces are responsible for their ODO structures, therefore causing variations in donation and transplantation policy and outcomes, data collection, and public reporting [14,17].

Incomplete or inaccurate data influences deceased organ donation policy and contributes to differences in donation activity across jurisdictions (both nationally and internationally). A primary consequence is a variation in access to deceased donor transplantation and disparities in wait times for patients [14].

A key recommendation to overcome these challenges is that government policy should mandate the collection and submission of referral data as a tool to promote access to transplantation, increase donation rates, and to better understand the barriers and facilitators in the referral process [18].



In 2019, Health Canada funded the Pan-Canadian ODT Data and Performance Reporting System Project to “support improvements in ODT access, care and outcomes across Canada through the deployment of technology solutions, system integrations and pan-Canadian data and system-level performance reporting” [17]. This collaborative work is ongoing in partnership with federal and provincial stakeholders who are designing a system that will respond to public reporting, quality improvement, and research needs.

## Examples of Data Collection and Public Reporting

### CANADA

- [Canadian Organ Replacement Register](#)
- [Canadian Blood Services System Progress Data Reporting](#)
- [Trillium Gift of Life Network](#)

### INTERNATIONAL

- [Australia's Donate Life](#)
- [UK's NHS Blood and Transplant](#)
- [United States' United Network for Organ Sharing \(UNOS\)](#)

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