

## Clinical Process Instruction Manual

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### Disclosure of Donor and Recipient Personal Information to External Stakeholders during Offering, Acceptance and Recovery Process Instruction

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#### Policy:

Trillium Gift of Life Network (TGLN) discloses “Personal Information” (PI) under the authority of the *Trillium Gift of Life Network Act* to designated facilities (including hospitals, transplant programs and tissue banks), physicians and Ministry employees. Any disclosure must be for a purpose related to organ and tissue donation or transplantation. PI means identifying information about an individual in verbal or recorded form as defined by the *Freedom of Information and Protection Act* and the *Personal Health Information Act*.

TGLN collects comprehensive donor and recipient information for the purposes of registering potential donors and patients in TGLN’s database systems (iTransplant and TOTAL). This information is required to assess suitability for organ and tissue donation, match donor organs to recipients waiting for an organ transplant, offering and the acceptance of organs and tissues for transplantation. TGLN collects recipient information from transplant programs as part of maintaining organ-specific waiting lists.

In order to facilitate life-saving and enhancing organ and tissue donation for transplantation, TGLN is required to provide donor and recipient information to Organ Procurement Organizations (OPOs) within Canada, the U.S. (United Network for Organ Sharing; UNOS), transplant programs, recovery programs, tissue banks and Canadian Blood Services. This is for the purposes of offering, accepting and recovering organs and tissues. TGLN limits the PI it shares with these stakeholders to only PI required for administrative and medical purposes related to the organ and tissue donation-transplantation process. TGLN takes best efforts to ensure that PI disclosed to stakeholders will not reasonably lead to identification of an individual, where not required to facilitate donation and/or transplantation. To ensure consistency and to minimize risks of identifying a donor or recipient, TGLN has established parameters around what information regarding a donor or recipient can be shared with stakeholders at the offering, acceptance and recovery stages of the donation-transplantation continuum.

For tissue donation, tissue banks are the source establishment of tissue donors. TGLN collects tissue donor information, accordingly on behalf of the tissue bank. TGLN will share the full, identifiable donor chart with the tissue bank, where they have accepted tissue. TGLN will share the donor chart with the tissue banks in a secure manner.

For the purposes of this document, the TGLN Coordinator may be the Referral Triage Coordinator (RTC), Clinical Services Coordinator (CSC), Organ and Tissue Donation Coordinator (OTDC),

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Surgical Recovery Coordinator (SRC), Tissue Coordinator (TC) or Tissue Recovery Coordinator (TRC).

#### Process:

1. PI is defined as identifiable information that TGLN holds relating to potential donors, patients on the waitlist, transplant recipients and their respective next of kin. PI includes, but is not limited to:
  - Name (first, last)
  - Gender
  - Age/Date of Birth
  - Contact information (telephone number or address)
  - Donor or Recipient hospital name and telephone#
  - Blood type
  - Description of their physical health
  - OHIP #
  - Physician's name
  - Race
  - Ethnicity
  - Religion
2. TGLN coordinators are responsible for redacting PI on documents, images and reports, when required.
3. TGLN coordinators will share information based on the matrix that outlines the stakeholder's need for information (either redacted or not) during each stage of the donation process and where the information can be found. See Exhibit 1.
4. TGLN coordinators must use a secure method to transmit documents that contain PI. Methods for transmitting include, but are not limited to, use of the One Mail system, secure file sharing, encryption, password-protection and fax. The One Mail system is an email platform that includes content encryption between sender and recipient accounts, allowing health care professionals to send patient information securely between registered users. TGLN held information shall not be sent to a stakeholder who is not a part of the One Mail system (i.e., personal email addresses), unless other security measures are used with IS or manager approval.

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5. No TGLN employee shall request a TGLN employee or a non-TGLN employee to send patient or chart information, PI, whether in written or image format, to TGLN via their personal devices and/or personal email addresses. Similarly, no TGLN employee shall send patient or chart information, PI, whether in written or image format, to TGLN via their personal device and/or personal email address. Any patient or chart information must be sent via an encrypted device.
6. Without explicit consent of the appropriate substitute decision maker, no TGLN employee shall take a video of a potential or actual donor, even if the individual is not identifiable, via a personal or TGLN device.
7. Sharing of limited PI is not intended to impede TGLN's role in facilitating donation and transplantation. Where time is limited, the manager-on-call (MOC) can be consulted to determine if an exception to the disclosure guidelines may be made to ensure that a donation opportunity is not lost or when there is uncertainty on the part of the TGLN employee about sharing PI.
8. Where an exception is made, and a hardcopy of PI is shared to facilitate donation and transplantation, the TGLN employee will ask the stakeholder to destroy the file containing PI after viewing and confirm to TGLN in writing that this has been done, or, return the file containing PI to TGLN for destruction.
9. The TGLN employee will document all instances where exceptions to sharing of PI have been made in the donor chart and will notify the Clinical Specialist for appropriate follow-up regarding destruction of hardcopy PI that has been shared.
10. TGLN will not disclose a record to a stakeholder or TGLN staff unless it is to support a donation case or to perform an assigned operational task linked to that record.
11. When a request for records (with or without PI) is received from a stakeholder or TGLN staff that is not required to support a donation case or to perform an assigned operational task linked to the record (i.e., research request), the TGLN staff member will direct the request to their immediate manager for review.
12. If there is a situation where a breach of privacy is suspected or has occurred as a result of disclosure, the TGLN employee must immediately report it to their manager and TGLN's Privacy Officer.



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#### Records:

- None

#### References:

- None

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### Disclosure of Donor and Recipient Personal Information to External Stakeholders during Offering, Acceptance and Recovery Process Instruction

#### Exhibit 1: Sharing of Personal Information with Stakeholders: Organ and Tissue Offering, Acceptance & Recovery

CSF-9-138

#### Sharing of Personal Information with Stakeholders: Organ and Tissue Offering, Acceptance & Recovery

Stakeholder	Offering			Acceptance & Recovery		
	Information Shared - iTx	Information Shared - Attachments	Recipient Information - TOTAL	Information Shared - iTx	Information Shared - Attachments	Recipient Information - TOTAL
Canadian OPO & UNOS	- Donor Chart with PI	- ABO with PI - HLA typing - Serology - Diagnostic Tests* with PI	- National ID# - TGLN # - age/DOB - sex	- Donor chart with PI	- Consent form with PI - MSHx with PI - Donor OR data with PI	- National ID# - TGLN # - age/DOB - sex
Transplant Programs (including fellows, recipient coordinators, labs etc.)	- Donor chart without PI (Exceptions: DOB, sex, TGLN# only)	- Diagnostic Tests* without Identifying PI (Exceptions: DOB, sex, TGLN# only) - Serology without PI (Exceptions: DOB, sex, TGLN# only) - Picture of an organ	- Recipient info with PI for patients at own centre only	- Donor chart without PI (Exceptions: DOB, sex, donor hospital name, TGLN# only)	- ABO without PI (Exceptions: DOB, sex, TGLN# only) - MSHx without PI (Exceptions: DOB, sex, TGLN# only) - Donor OR data (Exceptions: DOB, sex, TGLN# only)	- Recipient info with PI for patients at own centre only
Tissue Banks	- Donor Chart with PI	- Consent form with PI - MSHx with PI - Diagnostic Tests* with PI	---	- Donor chart with PI	- Consent form with PI - MSHx with PI - Diagnostic Tests* with PI	---
CBS for purposes of NOW and HSP registries	- Donor chart with PI	---	- Recipient info with PI	- Donor chart with PI	---	- Recipient info with PI for organ transplanted
Public Health Labs	All donor information may be disclosed to PHL for the purposes of investigation or case follow-up			All donor information may be disclosed to PHL for the purposes of investigation or case follow-up		

\* Diagnostic tests include but are not limited to: pathology reports, previous medical records, chest x-rays, ultrasound results, cardiac angiogram, biopsy results