

## Privacy Notice to Canadian Transplant Registry (CTR) Participants

### Purpose

The Canadian Transplant Registry (CTR) is an information system and database managed by Canadian Blood Services. The CTR is used to match donor organs to people who need an organ transplant. People who need an organ transplant and are healthy enough to receive a transplant are known as transplant candidates. The donated organs may be from living donors or deceased donors, depending on which Registry program the transplant candidate is participating in.

Canadian Blood Services is committed to protecting the privacy and security of personal information in its custody. This Notice explains how Canadian Blood Services collects, uses, retains and shares the personal information it collects or receives about organ donors and transplant candidates participating in the CTR.

### Definitions

**Human Leukocyte Antigen (HLA) Typing:** Lab testing done on organ donors and transplant candidates. HLAs are proteins found on most cells in the body. A person's immune system uses these proteins to recognize which cells belong in his or her body and which do not. The immune system will try to reject things with HLA proteins that do not look familiar, such as a transplanted organ. HLA typing is used to match potential donors with transplant candidates to minimize the likelihood that the candidate will reject the transplanted organ.

**Organ Donation Organization:** The organization responsible for coordinating distribution of all deceased organ donations within a geographic region.

**Referral Centre:** A hospital program that does not have a surgical transplant program.

**Living Donation Program:** A specialized hospital program where individuals are evaluated to see if they are healthy enough to be a living organ donor.

**Transplant Centre:** A hospital with an organ transplant program that evaluates transplant candidates for transplant eligibility and performs the transplant surgery.

**CTR Record:** The portion of your personal information that is stored in the CTR. It contains your personal information needed for matching.

## What Personal Information Do We Collect?

When you participate in the CTR, your personal information may be entered in the CTR by your organ donation organization, living donation program, transplant program, referral centre or Canadian Blood Services. Your personal information may be collected from you, your hospital, your laboratory or other medical records and may include the following:

- Contact information, such as your name, address and telephone number;
- Sex, ethnicity and date of birth;
- Provincial health insurance number;
- Health information, including medical test results, and social information;
- The type of organ(s) you need if you are a transplant candidate;
- HLA typing results and your blood group;
- Information about your surgery and surgical outcome, including test results; and
- Your long-term health outcome data, including test results.

## How Do We Use Your Personal Information?

Your personal information is collected and kept in the CTR to match transplant candidates with suitable donor organs. Your personal information may also be used to:

- Update and maintain your record in the CTR;
- Assess the compatibility of potentially suitable living or deceased organ donors with transplant candidates;
- Manage offers of potentially suitable donor organs for transplant candidates;
- Improve organ donor and transplant candidate matching;
- Understand and improve long-term health outcomes for living organ donors and transplant recipients;
- Contact you about opportunities to provide feedback about our programs and services;
- Measure and improve the performance of the CTR and the organ donation and transplantation system in Canada, including analytics;
- Contact you about opportunities to participate in voluntary research if you consented to this contact;
- Contact you for safety reasons, if necessary;
- Comply with legal and regulatory requirements; and
- Fulfill any other purposes as permitted or prescribed by law.

## Who Do We Share Your Personal Information With?

Your personal information may be shared with the following:

- Transplant and referral centres that list transplant candidates in the CTR and who review the medical suitability of potential donors matched to transplant candidates;
- Living donation programs to assess potential living organ donors who have been matched with the programs' transplant candidates;
- Organ donation organizations and HLA laboratories to identify and confirm transplant candidates that are potential matches for donor organs;
- Auditors assessing the CTR;
- Medical researchers if you consented to being contacted about opportunities to participate in voluntary research and the research is approved by an independent research ethics board; and
- Others as permitted or required by law.

## How Do We Protect Your Personal Information?

Access to your personal information is restricted to Canadian Blood Services staff who need access to this information to perform their jobs. All Canadian Blood Services employees sign confidentiality agreements and receive privacy training.

Canadian Blood Services grants access to the CTR to only those living donation programs, transplant programs, referral centres, organ donation organizations and HLA laboratories with whom Canadian Blood Services has agreements to maintain the privacy and confidentiality of your personal information. Employees from these organizations who have access to the CTR sign confidentiality agreements before being granted access to the CTR database.

## Inactivation of Your CTR Record

Your transplant or living donor coordinator has the ability to inactivate your CTR record. This means that your personal information will not be used for matching during the inactivation period, but personal information about you will still be collected and added to your CTR record.

## Locking Your CTR Record

If you do not want any more of your personal information collected and added to your CTR record, please contact your transplant or living donation coordinator. Ask them for a *CTR Withdrawal of Consent for Further Collection of Personal Information* form to sign and return to Canadian Blood Services. The personal information collected about you up to the date of your consent withdrawal will remain in the CTR and continue to be used and shared, as outlined in



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the *Privacy Notice to Canadian Transplant Registry (CTR) Participants*. No further personal information about you will be collected.

*IF YOU WITHDRAW YOUR CONSENT TO FURTHER COLLECTION OF PERSONAL INFORMATION, YOUR PERSONAL INFORMATION WILL NO LONGER BE USED TO MATCH YOU FOR ORGAN DONATION OR TO RECEIVE AN ORGAN TRANSPLANT.*

## **HOW TO CONTACT US**

For questions relating to your CTR record please contact the living donation program or the transplant centre that you are registered with.

For questions or concerns about this Notice, please contact Canadian Blood Services' Privacy & Access to Information Office:

**Toll Free:** 1-877-262-9191

**Email:** [privacy@blood.ca](mailto:privacy@blood.ca)