Notice to Obtain Consent from Patients Participating in the Canadian Transplant Registry (CTR)

Purpose

The Canadian Transplant Registry (CTR) provides a national listing of patients waiting for a heart, kidney, lung, liver, pancreas, small bowel or multi-organ transplant and a national listing of highly sensitized patients waiting for a kidney transplant. If an organ donor becomes available, organ procurement organizations will search the CTR to identify patients who may be a potential match for transplantation.

Definitions

HLA Test Results: Human leukocyte antigen (HLA) typing is used to match patients and donors for organ transplants. HLA are proteins or markers found on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not.

Organ Procurement Organization: Is the organization responsible for coordinating all organ and tissue donations within a particular geographic region.

Personal Information: Is information that is used to identify you or that allows you to be identified; for example, your name, address, telephone number, date of birth, and includes personal health information.

Personal Health Information: Includes any information regarding your medical profile or condition such as your medical history, laboratory test results, health care number, etc., and includes transmissible diseases, blood group and HLA test results.

Referral Centre: Is a facility that refers patients requiring an organ transplant to a transplant centre to be listed on the CTR.

Transplant Centre: Is the facility where patients requiring an organ transplant are listed on the CTR and where the organ transplant is expected to occur.

Collection of your Personal Information by the Canadian Transplant Registry (CTR)

In order for you to participate in the CTR, your personal information will be collected by your transplant centre, your referral centre or by the organ procurement organization associated with your transplant centre and used to create a CTR record for you. This personal information may be collected from you, your hospital, your laboratory records or other medical records. Your personal information will be put into the CTR which is operated by Canadian Blood Services in Ottawa, Ontario. The CTR is a web-based business application that is accessed through a computer system.

Personal information in your CTR record may be used to:

- update and maintain your medical status;
- identify you as a potential match with an organ donor;
- determine your HLA compatibility with an organ donor;
- manage offers of potentially suitable donor organ(s) received from an organ procurement organization;
- contact you in the event that a compatible match is found;
- contact you regarding opportunities to participate in voluntary research;
- comply with legal and regulatory requirements, if required; and,
- fulfill any other purposes prescribed by law.
Personal information in your CTR record may be disclosed:

- to health care professionals and medical data clerks at transplant centres and referral centres responsible for your care;
- to health care professionals and medical data clerks at organ procurement organization’s within Canada and their associated HLA laboratories when they access the CTR directly or when your personal information is downloaded into the organ procurement organization’s computer system, (NOTE: Canadian Blood Services will only permit organ procurement organization’s to download your personal information if they have entered into a Data Sharing Agreement with Canadian Blood Services to keep your personal information confidential);
- to public health authorities, auditors, or others as permitted, or required, by law;
- to medical researchers needing to contact recipients or potential recipients about volunteering for participation in research that has been approved by a research ethics board, if you consent; and,
- for any other purpose prescribed by law.

In addition, in accordance with applicable laws in your jurisdiction, Canadian Blood Services may use or disclose personal information from your CTR record, but which does not identify you, to support approved research, continuous process improvement, long-term analytics and organ allocation policy.

If you receive a transplant, personal information about your surgery and surgical outcome will be entered into your CTR record. Your transplant centre will also continue to monitor your health and the function of your organ after your surgery. Personal information, including medical test results from your hospital stay and follow-up visits with your transplant team, may be entered into your CTR record. This personal information may be used to measure the success of the CTR, improve the matching of donors and recipients in the future, and understand any long-term outcomes for people receiving organ transplants through the CTR.

Our Commitment to Your Privacy

Canadian Blood Services is committed to protecting the privacy and security of your personal information in the CTR. We do so by following relevant laws and best practices.

Canadian Blood Services will grant access to the CTR only to those Canadian Blood Services staff members, health care professionals and medical data clerks at organ procurement organizations, transplant centres, referral centres and HLA laboratories who require access to the CTR in order to perform their job functions. All individuals who require access to the CTR are required to sign a pledge of confidentiality to keep your personal information confidential.

Withdrawing Consent

If you decide that you no longer wish to participate in the CTR, please contact your transplant centre and you will be given a form to sign and return to Canadian Blood Services. All of your personal information that has been collected up to the date of your withdrawal of consent will remain in the CTR, but no further personal information about you will be collected, used or disclosed by the CTR. Canadian Blood Services will use your personal information to contact you for safety reasons, if necessary.

IMPORTANT NOTICE: IF YOU WITHDRAW YOUR CONSENT PRIOR TO RECEIVING A TRANSPLANT, YOUR CTR RECORD WILL NO LONGER BE AVAILABLE TO ORGAN PROCUREMENT ORGANIZATIONS ACROSS THE COUNTRY FOR THE PURPOSE OF IDENTIFYING YOU AS A POTENTIAL MATCH FOR A DONOR ORGAN.
How to Contact Canadian Blood Services

Canadian Blood Services respects your right to access and request correction of your personal information. You may contact our Privacy & Access Office for more information about our privacy and access practices, or to request access to or correction of your personal information as follows:

- **In writing:**
  Canadian Blood Services
  Privacy & Access Office
  1800 Alta Vista Drive
  Ottawa, ON K1G 4J5

- **By phone:**
  1-613-739-2483
  1-877-262-9191 (toll free)

- **By e-mail:**
  Privacy Office – privacy@blood.ca
  Access to Information office – ati@blood.ca

More information regarding Canadian Blood Services’ privacy practices can be found on our website at: www.blood.ca.

If you feel your concerns have not been addressed by Canadian Blood Services you have the right to contact your provincial Privacy Commissioner or Privacy Ombudsman. Look on our website for their contact information.
Consent for Patients to Participate in the Canadian Transplant Registry (CTR)

I, ____________________________________________________
___________________________________
(Print FULL NAME and ADDRESS)

consent to participate in the Canadian Transplant Registry (CTR) as a patient waiting for a heart, kidney, lung, liver, pancreas, small bowel or multi-organ transplant, or as a highly sensitized patient waiting for a kidney transplant, and to have my personal information, entered into the CTR. I agree to the collection, use and disclosure of my personal information for the purposes described in, and in accordance with the “Notice to Obtain Consent from Patients Participating in the Canadian Transplant Registry.”

I understand that by agreeing to participate in the CTR and having my personal information entered into the CTR I am not consenting to any medical procedures. If I am contacted by my transplant team about a potential transplant, and agree to proceed with the transplant, my transplant team will discuss the required consent for medical procedures, including surgery, with me.

(Required) Signature of participant (patient):

Participant’s Signature
Date (yyyy-mm-dd)

Or:

Signature of the person legally authorized to consent to the collection, use and disclosure of the participant’s personal information.

Print Full Name
Date (yyyy-mm-dd)

(Required) Witness to Participant’s or Legally Authorized Person’s Signature:

Witness’ Signature
Print Full Name
Date (yyyy-mm-dd)

Preferred Language of Correspondence:  ☐ English  ☐ French

I am willing to be contacted about participating in voluntary research:  ☐ Yes  ☐ No

Please keep one signed copy for yourself and return 2 signed copies to your transplant coordinator. Your coordinator will keep one copy on your medical chart and send one copy to Canadian Blood Services.
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