

CIBMTR protects your personal data

The CIBMTR (Center for International Blood and Marrow Transplant Research) works with scientists around the world to improve care for people with blood cancers and other diseases. The CIBMTR studies treatments such as hematopoietic cell transplantation (HCT) and cellular therapies. Our medical research helps people live longer and feel healthier.

To study medical treatments, CIBMTR collects some personal data. **Personal data** is information about you. You have the right control your data. Here is how we collect, use, store and protect your data. As a scientific research organization, we obey these privacy laws:

- the U.S. Health Insurance Portability and Accountability Act (HIPAA)
- the European Union’s General Data Protection Regulation (GDPR)

We do not release confidential data or any data that you restricted in a signed consent form.

Why is personal data gathered?

The CIBMTR represents an international group of medical researchers. We record how well different treatments work. Then, we publish the results. Our scientific studies do not use your name or other information that identifies you. Our research helps doctors and people choose the best treatments.

How is personal data obtained?

Medical centers send data from medical records to the CIBMTR through a secure computer system.

What personal data is sent to the CIBMTR?

If you get HCT or cellular therapies, the CIBMTR may get some of your data. This may include:

Personal data	Health data
Name, address, birth date, birth location, gender, mother’s maiden name, ethnicity, race, marital status, occupation, work status, education and health insurance	Diseases, lab results, drugs, treatments, genetic data, outcomes of treatment, medical diagnosis or procedure codes, donor, and transplant center

In most cases, **we remove all data that could personally identify you**, such as your name, address and more. We keep that data in a separate database from your health information. We replace your name and other information that identifies you with an anonymous number, called the CIBMTR ID number. This is called **de-identified data**. De-identified data do not have information that identifies you, donors, or medical centers.

We protect your privacy. Our Institutional Review Board monitors us.

How are personal data used?

- We use data only for scientific research;
- We use the smallest amount of data needed for research;
- We erase data when the program no longer needs it;
- We keep data secure and confidential;
- We use data only as allowed by law or by your signed consent forms.

How do we store and protect your data?

CIBMTR stores data in a secure database in the United States. We safeguard the data. Each year, an auditor checks our security. We follow rules from:

- the National Institute of Standards and Technology (NIST 800-53)
- the U.S. Federal Information Systems Management Act of 2002
- the U.S. Health Resources & Services Administration

How are data transferred?

A researcher can request medical data for a scientific study. CIBMTR follows scientific and ethical rules to approve or deny the project. Institutional Review Boards monitor the researchers.

In most cases, only de-identified data are provided for the study. For example, a researcher studying a cancer treatment might request data about diseases, treatments, and types of transplant. Many people's data would be combined for the study.

Sometimes, some personal data may show how well treatments worked in certain groups of people. In that case, researchers may want to know the patients' age or gender, or the date and location of transplants.

Your Rights

You have the right to:

- Know whether and how your data are being used;
- Know which data are being used;
- Know who has your data;
- Access information on your data;
- Fix inaccurate or incomplete data;
- Withdraw consent for your data to be used in the future;

You may have additional rights granted by local laws.

If you wish to use these rights, please email CIBMTR-DataProtection@mcw.edu, or mail a letter to:

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Medical College of Wisconsin
9200 W Wisconsin Ave, Suite C5500
Milwaukee, WI 53226

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