

Title:

**Section 20.0 NZBMDR STANDARDS
PRIVACY POLICY**

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SECTION 20.0 NZBMDR STANDARDS Privacy Policy

20.1 Background

The New Zealand Bone Marrow Donor Registry (NZBMDR) is a national organisation holding information on Donors and Patients throughout New Zealand.

The NZBMDR is bound by the **Health Information Privacy Code 1994**, incorporating amendments. The Code includes Privacy Principles that set out how private sector organisations should collect, use, keep secure and disclose personal information.

The principles also give individuals a right to know what information an organisation holds about them and the right to amend incorrect data. There are special provisions for sensitive health information.

20.2 The Privacy Act gives a donor a number of rights including the following:

- The donor must be told why personal information is being collected and whether it will be given to other agencies.
- The donor has the right to request access to the information held and if necessary to have it amended so that it is accurate, complete and up to date.
- The donor has the right to have personal information stored securely and protected from unauthorised access or misuse.
- The donor has the right to know how personal information will be used.
- If the donor believes their privacy has been infringed they can make a complaint.(20.8)

20.3 What information is held

- Donors

The NZBMDR holds personal information supplied by each donor. This information includes birthdate, sex, ethnicity, and contact details

In addition, HLA tissue typing information, blood group and blood donor ID number and NHI is held. Results of infectious disease testing, medical history and other medical tests are performed if a donor matches a recipient.

- Recipients

The NZBMDR holds information re age, sex, date of birth, ethnicity, weight, a brief medical history and current clinical status supplied by the transplant physician.

In addition, results of HLA tissue typing information, blood groups and some viral tests e.g. CMV are held.

20.4 Why we collect information

- Donors

Age, Sex, Blood Group and Ethnicity of donors is recorded as these donor characteristics are pertinent to a patient's choice of a donor.

Personal contact information and that of a contact person nominated by the donor, is used to maintain contact with donors.

Names, addresses and contact information are not released to search centres and do not appear on any search reports which are forwarded to other agencies.

If a donor is identified as a potential match for a specific patient, medical information will be collected from that donor to protect both the health and safety of the donor and the safety of the potential recipient of their stem cells

- Recipients

The NZBMDR holds information re NHI, date of birth, ethnicity, weight and HLA tissue typing from a recipient in order to accurately search for an appropriate donor for unrelated stem cell transplantation.

This information also serves to confirm the recipient's identity during this process.

In addition, blood groups and some viral tests are held to make a final selection if several donors are available.

20.5 Disclosure of information

Non-identifiable donor information such as Tissue Type, ABO Blood Grouping, gender and age will be provided to the Transplant Centres to assess compatibility to donate stem cells if a donor has been identified as a potential donor for a specific patient.

All Blood samples collected for Verification testing will be labelled with the donor unique ID number and a date of birth.

At no stage will the donor name, or contact details be released to other parties except the collection centre.

20.6 Access to information

Should a donor wish to see what information is held, they must submit a written request to the NZBMDR. Proof of identity will be required to ensure information is not disclosed to the wrong person.

20.7 Storage and security of information

Our security systems control access to record storage areas. These areas are locked 24 hours a day with entry by swipe card only during office hours and swipe card together with entry codes out of office hours. All electronic information is password protected. All staff is bound by the NZBMDR Public Relations and Confidentiality Guidelines, underpinned by the National Privacy Act.

Off site storage must be with a firm who can guarantee confidential storage facilities

20.8 Making a complaint

If a donor believes that their privacy has been infringed, their concern will be investigated by the NZBMDR Executive Officer. If the donor is not satisfied with the response they can discuss the issue with other personnel eg their general practitioner, can seek assistance through the Health Advocates Office, and/or refer the complaint to the Privacy Commissioner.