



ABDR/MyABDR Privacy Collection Notice

The ABDR and MyABDR are provided by the National Blood Authority (NBA) which is an Australian Government agency responsible for the supply of blood and blood products in Australia. The NBA provides the system in cooperation with individual Haemophilia Treatment Centres (HTCs) around Australia, the Australian Haemophilia Treatment Centre Directors' Organisation (AHCDO) and Haemophilia Foundation Australia (HFA).

This notice explains how your personal information in the ABDR and MyABDR will be managed and protected. A copy of the NBA's privacy policy can be found at <http://www.blood.gov.au/privacy>. This policy gives more details on how the NBA manages personal information and how you can make a privacy complaint to the NBA.

Why is my personal information collected?

The personal information about you that is collected in the ABDR and MyABDR includes your name and contact details, your diagnoses and treatment plan as well as your height and weight, what other health services you may use in your treatment of your bleeding disorder (such as physiotherapy, pathology and your doctor's appointments), the treatment products you receive, and whether you had any complications from your treatment.

This information is not your complete medical record. Rather, it is a special record of you and your bleeding disorder that your treatment team at your HTC can use to give you the best care and treatment for you. This information is also important for the NBA to make sure enough blood products are available to you when you need it. If you choose not to be in the ABDR then this will not impact your treatment. However, your doctor and haemophilia treatment team at HTCs around Australia will not be able to readily access your latest medical records as easily as they can if you are a part of ABDR. It will also be harder for the National Blood Authority to accurately forecast what products are required to treat people with bleeding disorders in Australia.

Sometimes, your treating HTC, other health professionals who treat you, the NBA and/or research staff from HFA and Australian Haemophilia Centre Directors' Organisation (AHCDO) may require reports using your information from the ABDR. These reports are used to help improve healthcare practice and to forecast and plan Australia's clotting factor supply. Reports that are published from ABDR will only give statistics and/or summaries that do not identify individuals. Therefore, you will never be identified from these reports.

What happens when I give my consent for the ABDR?

You can consent to being included in the ABDR either directly with your HTC by signing this consent form or by registering for MyABDR online. When you do so, from that point, staff at your HTC will enter your health and personal information that identifies you in the ABDR. This will include any information you enter into the MyABDR app or website. Once your information has been entered into the ABDR, it becomes an up-to-date record about your bleeding disorder condition that is used by your treatment team for your health care and the administrative support staff at your HTC to maintain an accurate record.

Who will access my personal information?

The ABDR Steering Committee manages the security and access to the ABDR so that only **authorised** users have access to the ABDR. This committee is made up of representatives of AHCDO, NBA, a State or Territory Government representative and HFA. The Steering Committee grants access to authorised staff of the NBA, AHCDO and HFA. This access is limited, controlled and managed to make sure the data is reliable, that the ABDR is used correctly, and/or provide reports for quality assurance and for research.

- Authorised NBA staff provide technical and user support for the ABDR and MyABDR, assist in managing the integrity of the data entered into the ABDR, and extract information for approved reports and research
- Authorised AHCDO staff help co-ordinate data entry at HTCs, and support good healthcare practice to improve the health and wellbeing of patients

Research is currently limited to developing clinical guidelines and undertaking benchmarking to improve treatment and care for people with bleeding disorders. Any additional research using information in the ABDR will only be undertaken in accordance with the requirements of the *Privacy Act 1988* (Cth).

How can I be confident that my personal information is protected?

Maintaining your privacy and appropriate confidentiality is a top priority to us and strict security rules, managed by the ABDR Steering Committee, are in place to guarantee patient privacy is maintained at all times. Only authorised staff from your HTC, the NBA and AHCDO can directly access your data to perform specified roles. Your information is kept on the ABDR database which is physically located in a secure data centre in Australia. These procedures protect your information from misuse, unauthorised access, interference, alteration, loss and/or disclosure.

Do I have to use my name to be included in the ABDR?

If you would prefer to be known by a name that is not your actual name (i.e. a pseudonym) for the purposes of your record in the ABDR and your registration in MyABDR, then you can do so if your HTC is able to implement this option without impacting on their ability to properly manage your records. Your HTC will still need to identify who you are to make sure the right information from your HTC medical record is entered into your ABDR record. If you choose to use a pseudonym in the ABDR then you will need to talk to your HTC about the availability of this option. Any MyABDR registration will then need to link to this ABDR record, by using the same pseudonym.

Can I access my personal information?

You have the right to access and seek correction of your personal information on the ABDR, in accordance with privacy laws. Your HTC is generally the best place to go first to access and seek changes to your personal information. If you are unhappy with the response from the HTC, you can contact the privacy commissioner in your State or Territory. You may also contact the NBA at privacy@blood.gov.au.

If I have changed my mind, how do I opt out of the ABDR?

The ABDR and MyABDR are voluntary and you have the choice to opt out at any time. If you gave consent to be included in the ABDR directly to your HTC then you will need to opt out by contacting that HTC directly. If you only consented to be included in the ABDR through registering for MyABDR, then you can opt out of both ABDR and MyABDR by changing your privacy consent status when you log onto MyABDR. Once you change your status on MyABDR then you can no longer enter your information into the app or website.

Record of consent

PRIVACY CONSENT:

The nature of the ABDR and MyABDR has been fully explained to me. I have understood the patient information and informed consent form and have received a copy to take away with me. I have had the chance to ask questions, and all my questions have been answered to my satisfaction. I consent to the recording of personal information (including sensitive health information) about me/my child in the ABDR.

Signature of patient: _____

Date _____

Signature of parent/guardian: _____

Date _____

(Required if the patient is a minor and unable to consent to medical treatment or otherwise lacks the capacity to consent)

ALTERNATIVE PRIVACY CONSENT WITH PSEUDONYM:

The nature of the ABDR and MyABDR has been fully explained to me. I have understood the patient information and informed consent form and have received a copy to take away with me. I have had the chance to ask questions, and all my questions have been answered to my satisfaction. I consent to the recording of personal information (including sensitive health information) about me/my child in the ABDR, via the use of a pseudonym.

Preferred pseudonym: First name: _____

Last name: _____

Signature of patient: _____ Date _____

Signature of parent/guardian: _____ Date _____

(Required if the patient is a minor and unable to consent to medical treatment or otherwise lacks the capacity to consent)

ALTERNATIVE FOR HTC STAFF RECORDING ORAL/TELEPHONE PRIVACY CONSENT:

Declaration: I have supplied a Patient Information Statement and Informed Consent form to the patient (or parent/guardian of the patient if the patient is a minor and unable to consent to medical treatment or otherwise lacks the capacity to consent). I believe that they understand the purpose, extent and possible risks of their/their child's involvement in this project. They are aware of the purpose of the collection of their personal information and have a copy of the Privacy Collection Notice.

Name and position of person obtaining consent: _____

Signature of person obtaining consent: _____

Date: _____ Time: _____

Patient wishes to use pseudonym: Yes/No

Preferred pseudonym: First name: _____

Last name: _____