



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.

The primary purpose of collecting your personal information in ABDR is to use it as a special medical record of you and your bleeding disorder that your treatment team at your HTC can use to give you the best care and treatment. ABDR information is also used in research to improve treatment and care for people with bleeding disorders. The NBA will also use ABDR information to monitor supply and use of treatment products, and to plan for production and supply of blood products and services. If you choose not to be in the ABDR then your information will not be available to you or others through ABDR or MyABDR. This will not impact your access to treatment.

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