



## Patient Information and Informed Consent

### Information for patients

We request that you/your child register in the Australian Bleeding Disorders Registry (ABDR). If you/your child have been getting treatment and care for your/their bleeding disorder, you/they may already be registered, and we ask that you/your child continue being a part of the ABDR. Before you do, it is important that you understand what is involved and what will be done with the information you provide. This form contains answers to some of the questions you might have. At the end of this form is a section for you to sign to confirm you agree to participate. If you have any questions after reading this form, please contact the relevant person before signing this form. You will find a list of contact details on the next page.

#### What is the ABDR?

The Australian Bleeding Disorders Registry (ABDR) is a computer database of healthcare information about people with bleeding disorders. This information recorded includes your name and contact details, information about your health and treatments (such as your height and weight, diagnoses, treatment plan and use of treatment products), what health services you have used (such as doctors' appointments and hospital admissions), and whether you faced any complications through your treatment.

The ABDR is not your hospital medical record. The ABDR is a special medical record about you and your bleeding disorder condition that is separate to other hospital and/or health care service medical records.

#### How will the ABDR help me?

ABDR helps your doctor and other health professionals in your treating team at your Haemophilia Treatment Centre (HTC) to understand your care and treatment needs, and is used to check which treatments work best for you to improve your health and wellbeing. If you travel, or move interstate, you can say if you want this medical record to be available to specified staff in HTCs around Australia. The ABDR also helps Government to plan so that there are enough treatment products in Australia to meet the needs of all patients with bleeding disorders.

#### I have heard of MyABDR. What is it?

MyABDR is a secure app for smartphones and a computer website for people with bleeding disorders or parents/caregivers. The MyABDR app and website link directly to the ABDR. You can use MyABDR to record home treatments and bleeds and manage treatment product stock. If you don't want to use the app or website, you can use the MyABDR paper-based treatment diary. No other apps, websites or treatment diaries will link directly to the ABDR.

If you agree to use MyABDR, you will enter the information about your bleeds, treatment and product stock using the app or website. The information you enter into the MyABDR app or website will be available in the ABDR system used by your treatment team at your HTC as soon as you transmit it. You will be able to check all the information you enter later on the app or website.

You can get more information about MyABDR from your doctor at your HTC or by visiting <http://www.haemophilia.org.au/foundationsandservices/myabdr>.

#### Which patients can join the ABDR?

Australians diagnosed with a bleeding disorder are eligible to join. These bleeding disorders include:

Haemophilia A, B, and C	von Willebrand disease (1, 2, 2A, 2B, 2M, and 3)
Other factor deficiencies (e.g. Factor II, V, X, XII, XIII)	Fibrinogen disorders
(A)Symptomatic carriers (Haemophilia A and B)	Platelet disorders
Acquired bleeding disorders	Vascular disorders



### **What do other patients think of the ABDR?**

The ABDR is not new – it has been around since 1988 when it was first funded by the Haemophilia Foundation Australia (HFA). There are now more than 5000 patients in the ABDR, which includes most HTC patients in Australia. They think it is important for their information to be in the ABDR so that they get the treatment and care they need. The ABDR is now provided by the National Blood Authority, an Australian Government Agency.

### **How do I register for the ABDR or MyABDR?**

If you consent to being included in the ABDR, then your treating doctor and treatment team at your HTC will register you and give you a copy of this form to keep if you want to look at it again later. If you would like to register for MyABDR at a time convenient to you, then go to <http://www.blood.gov.au/myabdr>.

### **What if I don't want to be in the ABDR, will it affect my treatment?**

The ABDR is completely voluntary. You can opt out of the ABDR at any time. 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.

### **What about my privacy?**

Any personal information about you that is collected and held in the ABDR is protected by law, including the *Privacy Act 1988* (Cth). The attached privacy collection notice explains how your privacy and personal information is protected.

### **Who can I contact if I would like more information?**

You can get further information and assistance about ABDR or MyABDR from:

- The ABDR support team at the NBA - visit [www.blood.gov.au](http://www.blood.gov.au) or call 13 000 BLOOD (13 000 25663) or email [abdr@blood.gov.au](mailto:abdr@blood.gov.au)
- The Australian Haemophilia Centre Directors' Organisation (AHCDO) - visit [www.ahcdo.org.au](http://www.ahcdo.org.au) or call (03) 9885 1777 or email [info@ahcdo.org.au](mailto:info@ahcdo.org.au)

## **Endorsements**

### **Endorsement from Haemophilia Foundation Australia (HFA)**

Haemophilia Foundation Australia supports the ABDR. It helps doctors and other treating health professionals to understand more about the care and treatment needs of people affected by bleeding disorders. The ABDR will assist and guide planning to ensure treatment product is available when it is needed. We are confident the steps in place will mean accurate, reliable and confidential data is available and that your personal information is protected.

[www.haemophilia.org.au](http://www.haemophilia.org.au)

### **Endorsement from Australian Haemophilia Centre Directors' Organisation (AHCDO)**

The ABDR is a valuable tool that provides a summary of those affected with haemophilia and other bleeding disorders in Australia. Data from the ABDR is the best information available for clinicians to advise governments making policy decisions regarding treatment needs and product availability.

National statistics available through the ABDR will give AHCDO an overview of practice and allow opportunities for improvement. This data can be pooled to compare Australian treatment standards with international benchmarks. The ABDR will continue to provide the ability to assess quality of life and other important clinical questions arising across Australia.

AHCDO's partnership on this initiative with the National Blood Authority, Haemophilia Foundation Australia and other specialist health professional groups is vital to the pursuit of excellence in clinical treatment practices.

[www.ahcdo.org.au](http://www.ahcdo.org.au)