

Frequently Asked Questions (FAQ)

FAQ sections:

- > About MyABDR
- > Getting Started with MyABDR
- > Using MyABDR
- > Access to Information
- > Security of Information
- > Use of Information

About MyABDR

What is MyABDR?

MyABDR is a secure app for smartphones and a computer website for people with bleeding disorders or parents/caregivers. You can use MyABDR to record home treatments and bleeds and manage treatment product stock.

There is also a MyABDR paper-based Treatment Diary as an alternative.

The MyABDR app and web site link directly to the Australian Bleeding Disorders Registry (ABDR). The ABDR is the system used by Haemophilia Centres around Australia for the clinical care of their patients.

Why use MyABDR?

MyABDR makes life easier for you, your family and your Haemophilia Centre.

- It makes it quick and easy for you and your family to record treatments and bleeds, stocktake and update contact details
- Your recorded treatment information will be at your fingertips - on your smartphone or your home computer.
- It will make record-keeping more efficient - Haemophilia Centres won't need to re-enter or upload online patient diaries into the ABDR

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or contact HFA www.haemophilia.org.au/myabdr T: 1800 807 173 E: hfaust@haemophilia.org.au

MyABDR is a collaboration between Haemophilia Foundation Australia (HFA), the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of all Australian governments

MyABDR helps you and your Haemophilia Centre to manage your care.

- Your Haemophilia Centre can keep track of what is happening for you or your family to see if there are any problems or if treatment plans need adjusting
- Statistics from the system can help specialist clinicians, researchers and advocates like Haemophilia Foundation Australia to study trends and patterns and work to improve treatment and care.

MyABDR works in with the national system to supply treatment product.

- You will be able to receive information about products or recalls
- Statistics about the amount of product being used can help the government to stocktake and plan for purchase of future supplies.

MyABDR will be around long-term.

- MyABDR will be ongoing - it is part of the national ABDR system.

What are the features of MyABDR?

- Quick, simple steps to record treatments
- Bleed details can be added to treatments
- Body map to help identify bleed location
- Areas for detailed notes
- Treatment plan details can be viewed online
- Reports of treatment and bleed histories on web site version
- Easy to use inventory section to manage stock at home
- Family logins to switch between multiple family members
- Updatable height and weight, contact and delivery address details
- Secure and private.

What is the ABDR?

ABDR stands for the Australian Bleeding Disorders Registry. It is a secure online system used nationally by all Australian Haemophilia Centres for clinical care of their patients. It includes an individual clinical record for each person with a bleeding disorder with details of their bleeding disorder, complications and treatments. More information can be found at <http://www.blood.gov.au/abdr>.

Is MyABDR simple to use?

Yes, MyABDR has been designed with the input of people with bleeding disorders, parents/caregivers and the health professionals who care for them to make sure it is simple, effective and friendly to use.

How much does the MyABDR app cost?

The MyABDR app is free.

Who looks after the ABDR?

The National Blood Authority (NBA) develops and maintains the Australian Bleeding Disorders Registry (ABDR) system for Haemophilia Centres. The ABDR was first established in 1988 and is upgraded regularly by the NBA in collaboration with Haemophilia Centres and the Australian Haemophilia Centre Directors' Organisation (AHCDO). The ABDR is overseen carefully by the ABDR Steering Committee. Its membership includes AHCDO, NBA, Haemophilia Foundation Australia (HFA) and a representative of federal and state government. It deals with issues such as privacy, ethics, system development priorities and data accuracy.

Supporting the ABDR system is an extension of the NBA's role in organising the supply of clotting factor treatment products for Australia.

Is MyABDR linked to ABDR?

Yes, the MyABDR secure app and web site link directly to the Australian Bleeding Disorders Registry (ABDR). MyABDR and the ABDR share information with each other. Your designated Haemophilia Centre staff can view all information you enter into MyABDR but cannot edit it.

Where did MyABDR come from?

MyABDR is a collaborative project between Haemophilia Foundation Australia (HFA), the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of all Australian governments.

The idea for MyABDR was proposed by HFA Council delegates in October 2011, when they unanimously proposed to approach AHCDO and together explore the feasibility of adopting a national system for patients to record their clotting factor usage. They recognised that the system would need to have a number of options, both online and print-based, depending on people's access to technology but wanted to make sure it was universal, patient-controlled and simple.

The aim of MyABDR is to support the delivery of best practice clinical care and treatment for people with bleeding disorders.

Who is paying for MyABDR?

The MyABDR project, like the Australian Bleeding Disorders Registry (ABDR), is funded by all Australian governments as part of the national arrangements for meeting the cost of blood and blood products and treatments for people with bleeding disorders.

Who controls the project?

The Australian Bleeding Disorders Registry Steering Committee is responsible for overseeing MyABDR. The Steering Committee is made up of representatives from the Australian Haemophilia Centre Directors' Organisation (AHCDO), Haemophilia Foundation Australia (HFA), the National Blood Authority (NBA) and state and territory government departments who fund treatment products.

The National Blood Authority is responsible for the development of the software. To enable the development team to continue to actively engage with the bleeding disorders community and to ensure

that the application is highly functional and useable by people with bleeding disorders, HFA has agreed to work in partnership with the NBA. HFA facilitated consultation with the bleeding disorders community to develop MyABDR and is providing the initial user education materials, training and support.

What types of information are stored in MyABDR?

MyABDR stores information about:

- Your Login details
- Your name, contact details and delivery address for treatment product
- Your inventory of treatment stock at home
- Your treatment product usage
- Your treatment plan
- Your bleeding disorder treatments
- Your bleed history
- Your height and weight
- Your notes/memos
- Notifications about product recalls and expiry

Who can use MyABDR?

MyABDR is available to all people with bleeding disorders who have been diagnosed with haemophilia A, haemophilia B, all types of von Willebrand Disease (VWD), or other factor deficiencies including fibrinogen, platelet dysfunction, acquired factor VIII inhibitor, acquired von Willebrand Disease and some vascular disorders.

Do I have to use MyABDR to get my clotting factor?

No. There are some great benefits if you choose to use MyABDR but it is not a requirement for receiving clotting factor products.

Can I still use a paper diary?

Yes, you are welcome to continue using a paper-based diary or spreadsheet if you wish. The use of MyABDR is optional. A paper-based diary and spreadsheet that are based on MyABDR are available if you would like to adopt the same system.

How fast is it to record a treatment?

The app and web site have been set up to make this a quick process, for example, with pre-set lists so that you can scroll down and select the right items. It will probably only take you a few seconds once you have the hang of it.

Can I record details of bleeds?

Yes, when you record a treatment for a bleed, you can also complete the bleeds section. It includes a body map to help you identify the location of the bleed and a notes field where you can write any details you would like to record.

I currently use a different application to track my bleeds and infusions. Why should I change to MyABDR?

Unlike alternative solutions, MyABDR is fully integrated into the Australian Bleeding Disorders Register (ABDR) making it quick and easy for your Haemophilia Centre doctor and other members of the haemophilia team to gain a more timely and accurate view of the data you enter on bleeds and treatments, which is very important in the delivery of best practice clinical treatment and care.

MyABDR also offers new and unique features that often are not supported in alternative applications such as family logins, an inventory section to manage your treatment stock and notifications about the expiry dates and recalls of treatment products.

Where can I get more information?

More information about MyABDR is available on the HFA web site at www.haemophilia.org.au/myabdr and on the NBA web site at www.blood.gov.au/myabdr.

Alternatively you can contact Suzanne O'Callaghan at Haemophilia Foundation Australia on 1800 807 173 or email socallaghan@haemophilia.org.au.

Getting Started with MyABDR

When can I start using MyABDR?

MyABDR will be available from March 2014.

How will I access MyABDR?

MyABDR can be accessed through an iPhone, android-based smartphone and through a standard internet connected computer using a login and password.

What smartphones are supported?

- iPhone 3 and later
- Android 2 smartphones and later

Windows smartphones are not currently supported.

Where can I get the MyABDR iOS (Apple) or Android app?

You can download the MyABDR app from Apple App store or Google Play (Android).

How will I sign up?

MyABDR registration is quick and easy and can be done online at www.blood.gov.au/myabdr or by creating an account when you open the app.

After you register your Haemophilia Centre staff will process your access to MyABDR. This may take up to 7 days.

Using MyABDR

What are my first steps after logging in?

Before you record a treatment in MyABDR, you need to enter the details of the treatment product you will be using for your treatment in your inventory.

Where do I record a bleed?

You can record bleed details when you are recording a treatment for the bleed.

- Start recording your bleed on the RECORD TREATMENT screen
- Select BLEED from the TREATMENT TYPE list
- RECORD BLEED will then appear immediately below TREATMENT TYPE
- Tap or click on RECORD BLEED. This will activate the bleed section.

You can then record a new bleed or select an existing bleed and record the treatment for the bleed.

You can also use the body map to help identify the location of the bleed and add any details in the notes box.

How do I record a follow-up treatment for a bleed?

Follow the steps for recording a bleed.

- When you tap or click on RECORD BLEED on the RECORD TREATMENT screen, it will display a list of existing bleeds.
- Select the bleed you are treating and record the treatment.

Can I see treatment information that my Haemophilia Centre entered into ABDR?

Yes, MyABDR is linked to the Australian Bleeding Disorders Registry (ABDR) and the treatment information entered by your Haemophilia Centre is shown alongside the treatments you have entered. You can see this in the list of treatments on the TREATMENTS screen.

I get my treatment at the hospital. Can I still record my treatment?

Yes, if you ask the staff at the hospital to show you the vials of treatment product before you have your infusion, you can record the details in your inventory and then record the treatment in the TREATMENT section. Haemophilia Centre staff may record this for you, so discuss your treatment recording preferences with them beforehand so that your treatment is not recorded twice.

Can I send messages to my Haemophilia Centre using MyABDR?

No, MyABDR does not include a messaging feature. You need to contact your Haemophilia Centre directly if you would like to pass on messages or ask questions about your treatment. It is important to

remember that MyABDR is a recording tool. Although you may have recorded treatments via MyABDR, your Haemophilia Centre may not see them until they next look at your record.

Can I share my login with others?

No. It is important to keep your login details confidential to protect the security of your information. There are special logins designed to be used by parents and other carers so that they can record treatments and bleeds and other information on behalf of their children or the people they are caring for who cannot record it for themselves.

Haemophilia Centres recommend individuals who have their own device, including children, register to get their own MyABDR User Account rather than sharing accounts within the family. MyABDR includes features to identify the individual recording information.

I have a few children. Do I need to log in and out for each child?

No, MyABDR has been designed to make recording easier for parents. When you login you will select the family member you are recording information about. The name bar near the top of the page includes a switch icon , so you can select the icon to switch to another family member from anywhere in the app.

Can someone else change the information I have entered?

Any MyABDR user who has access to the same family member can edit information entered by the other user with access rights. MyABDR includes features to identify the individual recording or editing information.

However, although your Haemophilia Centre can view all of the information you enter in MyABDR, they cannot change your entries.

Can I use MyABDR to update my contact details?

Yes. Your Haemophilia Centre will be notified when you update your contact details in MyABDR.

Can I use MyABDR to update my delivery address?

Yes – but you need to give your Haemophilia Centre 5 business days to update suppliers. If you have less than 5 business days, contact your Haemophilia Centre.

Can I print a copy of the information I enter?

Yes. You will be able to view graphs of your treatment information in the MyABDR website using the same login and password as the MyABDR Smartphone App. Future releases of MyABDR will enable you to extract your data into MS Excel and other popular programs.

Access to Information

How can I be confident information about me will be adequately protected?

MyABDR is an extension of the Australian Bleeding Disorders Registry (ABDR). The ABDR system, its management and operation, and access to it are tightly controlled.

The ABDR Steering Committee has the responsibility for managing the ABDR. The Steering Committee is chaired by one of the specialist doctors who is both a director of a Haemophilia Centre and a member of the Australian Haemophilia Centre Directors' Organisation (AHCDO). The Steering Committee also includes the Executive Director of Haemophilia Foundation Australia to advocate for the needs of people with bleeding disorders. Other members include representatives from the National Blood Authority and the federal and state governments. The Steering Committee reviews the development and updates to the ABDR, the type of information that is made available and to whom, the quality and accuracy of the data, research studies proposing to use data from the ABDR, and reports that are generated from the system. Maintaining the privacy and confidentiality of the people with bleeding disorders whose information is in the ABDR system is essential to this process.

In addition, stringent security protocols have been built into the ABDR system. These protocols control access to personal data making sure identifying information is only accessible by the haemophilia health professionals who provide your treatment and care and authorised support staff.

Every effort is made to make sure MyABDR and the ABDR adhere to the Guidelines for Federal and ACT Government World Wide Web sites issued by the Australian Privacy Commissioner and the privacy laws of each state and territory which apply to your Haemophilia Centre and the health professionals who work there. In particular, this includes the Information Privacy Principles of the Privacy Act 1988. For more information on the controls to protect your privacy, go to www.blood.gov.au/privacy.

What type of personal health information is exchanged via MyABDR?

MyABDR shares the following types of personal information with the ABDR system:

- Your Login details
- Your name, contact details and delivery address for treatment product
- Your inventory of treatment stock at home
- Your treatment product usage
- Your treatment plan
- Your bleeding disorder treatments
- Your bleed history
- Your height and weight
- Your notes/memos
- Notifications about product recalls and expiry

Who has access to the personal health information in the ABDR?

Only the haemophilia health care team, the data managers and the staff who provide administrative support at your Haemophilia Centre and Centres you are visiting have access to your personal information in the Australian Bleeding Disorders Registry (ABDR). Other authorised users only have access to limited, de-identified and/or summary information where all information that could identify the patient is removed to protect patient privacy.

A small team of systems administrators at the National Blood Authority are able to access all areas of the ABDR system for the purposes of supporting and maintaining the system. However, there are strict governance, security and privacy policies and procedures that are enforced to make sure that all access is logged, undertaken only for the correct purposes, and to make sure all sensitive and personal data is protected.

Will my employer be able to access my data?

No. Your employer will not be able to access your MyABDR data through the ABDR system.

However, if you use your smartphone or another mobile device for recording via MyABDR and you do not want people around you to have access to your personal health information, it is important that you are conscious of security on your phone or device. Log out of MyABDR after recording or set up a screen lock on your smartphone or device to make sure other people who pick up your phone or device cannot look at your information in the MyABDR app or web site.

Will the government be able to access my data?

No. Only health professionals and support staff at your Haemophilia Centre or Centres you are visiting and a small team of systems and data administrators at the National Blood Authority are permitted to access the areas of the ABDR system which include your personal information.. The NBA's technical staff members are able to access all areas of the system solely for the purposes of supporting and maintaining the system.

Other authorised users only have access to limited, de-identified and/or summary information where all identifying information is removed to protect patient privacy.

In addition, strict security and privacy policies and procedures are in place to make sure that only approved government employees have access to de-identified information. This is for the purposes of managing the supply of clotting factor products in Australia.

This access is strictly controlled and all access is logged and monitored to make sure it is only undertaken for the correct purposes and that all sensitive and personal data is protected.

How much of my personal information is shared with the government?

None of your personal information is shared with the government.

Some statistical information from the ABDR that does not identify individuals may be used by the government to estimate the demand for treatment product in the future.

Security of Information

How secure is the ABDR?

The ABDR has one of the highest levels of security available in Australia.

The personal health information of people with bleeding disorders that is currently being managed in the ABDR or added to by people with bleeding disorders via MyABDR is hosted by the National Blood Authority and housed in a highly secure data centre in Canberra. This centre has such a high level of security it also hosts other highly sensitive government information such as data belonging to the Australian Federal Police (AFP) and the Departments of Health and Human Services (Medicare, Centrelink, etc). The ABDR data is not connected to any other database in this centre, but has its own secure set of data banks.

The technology that is being developed for the ABDR and MyABDR and an online copy of the data in the ABDR are hosted in the National Blood Authority's secure offices in Canberra. They are inside an area that requires three levels of access. The security level is higher than that required by the Australian Signals Directorate. Weekly back-ups of the ABDR data are encrypted and held off-site by a provider that is endorsed by the Australian Signals Directorate.

All technical support staff who are approved to access the ABDR have a security clearance by the government agency that provides security clearances for the Department of Defence.

For those who are technically minded, some details follow:

The ICT production environment for the Registry is hosted by the National Blood Authority in a highly secure data centre in Canberra which has been certified by both the Defence Signals Directorate (who provide ICT security services for the Australian Government) and the Australian Security Intelligence Organisation (ASIO, T4 Branch). The same data centre hosts a range of other government agencies including the AFP and the Department of Human Services (i.e. Medicare, Centrelink, Family Assistance Office etc).

The ICT development environment and online replica of all database data is hosted in the National Blood Authority's secure offices inside a triple-layer access controlled area which exceeds the relevant ASIO T4 branch requirements. Off-site back-ups of the registry on magnetic tape are produced weekly and held off-site by an ASIO T4 endorsed provider with all tape contents encrypted at 256 bits.

The National Blood Authority's ICT systems, including the arrangements for the registry, meet or exceed the mandatory requirements for an UNCLASSIFIED (G) system in the Australian Signals Directorate's Information Security Manual (ISM).

All users with privileged access (ie system administrators, ICT support staff and software developers) have security clearances at or above 'Negative Vetting, Level 1' issued by the Australian Government Security Vetting Agency.

How is my health information protected when it is being transferred or exchanged?

When Haemophilia Centre staff enter information into the ABDR and it is transmitted to the central database hosted at the NBA in Canberra, their online session is encrypted with a very high level of security.

More technical information follows:

Haemophilia Centre staff who are under the supervision of investigators at each Haemophilia Centre enter data into the Registry which is available through a 128bit encrypted browser session using SSL-EV certificates issued by Thawte.

What security safeguards are designed to prevent my information from being “hacked”?

Your personal information, both while it is being transmitted and when it is in the ABDR, is protected by a series of electronic firewalls and other means of security. The first level of firewalls is monitored around the clock by the Defence Signals Directorate’s Cyber Security Operations Centre to check for potential intruders and prevent them from reaching the ABDR database. The ABDR database sits behind the second set of firewalls so that the ability of an intruder to access the ABDR is very low.

In more technical detail:

A series of firewalls and associated security devices protect the data both in transit and at rest and the primary firewalls are monitored 24/7 real-time by the Defence Signals Directorate’s Cyber Security Operations Centre (CSOC). The database and reporting servers sit behind the primary and secondary fire-walls and so the ability of an intruder to compromise the database and reporting servers is very low.

Use of Information

How will governments use MyABDR information?

When models of the demand for treatment product are developed, they are based on information available from MyABDR and data recorded in the ABDR, along with the current types of treatment plans in Australian Haemophilia Centres. The models are used to estimate product demand into the future. These estimates are critical to the NBA's contract negotiations with national and international suppliers of blood and blood products.

By understanding the demand for clotting factor products, the NBA can ensure these contracts cover worst case scenarios and make sure there is enough product available in the country at any given point in time.

A number of steps are taken to protect the privacy of people with bleeding disorders whose personal data is in the ABDR:

- All ABDR data available to governments is collated and de-identified (ie, statistics that do not identify individuals)
- There are strict policies and procedures that govern the ABDR and its security protocols.

How will my doctor use MyABDR information?

Your doctor, Haemophilia Centre staff and other health care professionals will have access to the information that their patients enter into MyABDR after it is transmitted to the ABDR. This data will be used to give a more timely and accurate view of their patients' bleeds and home treatments, which is very important in the delivery of best practice clinical treatment and care.