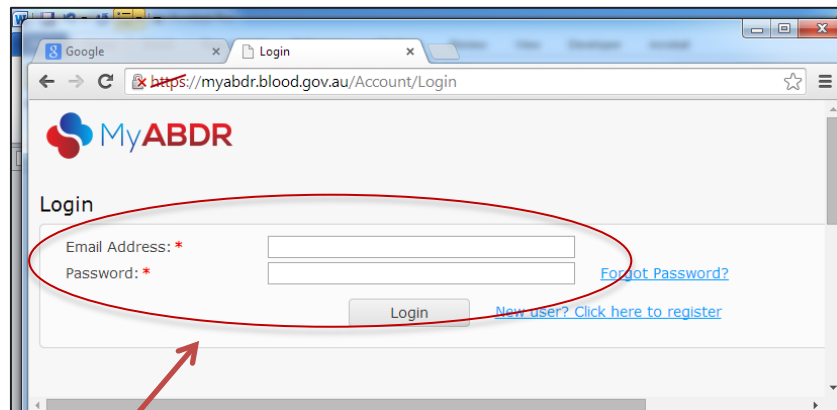


ABDR/MyABDR privacy consent form – MyABDR web site

Completing the form on the web site

1. Go to the web site - <https://www.myabdr.blood.gov.au>



2. Enter your email address and password to **login as usual**

HELP

T: 13 000 BLOOD (13 000 25663)
E: myabdr@blood.gov.au
W: www.blood.gov.au/myabdr

Or contact Haemophilia Foundation Australia
T: 1800 807 173
E: hfaust@haemophilia.org.au
www.haemophilia.org.au/myabdr

3. Select a patient

3.1 MyABDR account for one patient:

If this MyABDR account is only for one patient (eg, you or your child), the ABDR/MyABDR Privacy Collection Notice will be displayed at this point.



The screenshot shows a web form titled "Consent To Privacy" for user "Brendan STACKER [Change]". The form contains the following text:

Please read this notice and complete the Consent Form below before continuing to use MyABDR.

The Privacy Collection Notice was last updated on 11/12/2014

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?

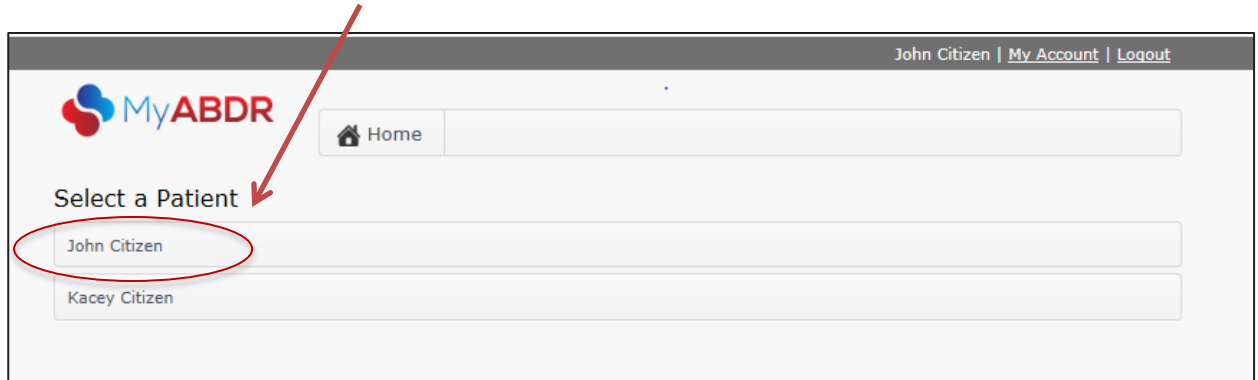
The personal information about you that is collected in the ABDR and MyABDR includes your name and contact details, your diagnoses and treatment plan as well as your height and weight, what other health services you may use in your treatment of your bleeding disorder (such as physiotherapy, pathology 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 treatment

Go to **step 4** for instructions on completing the consent form.

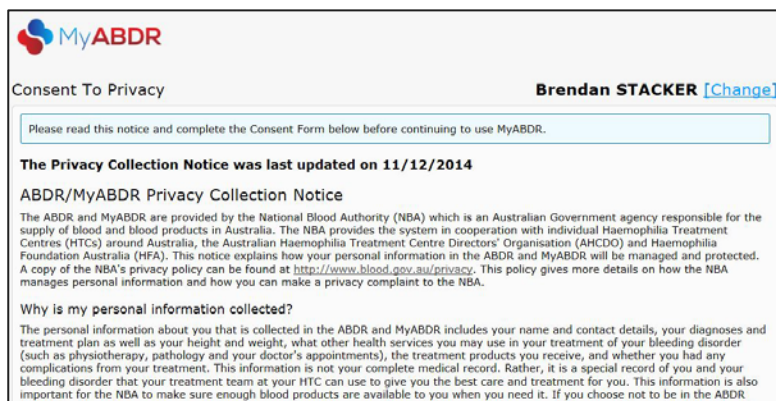
3.2 MyABDR account for two or more patients (eg, where you switch between two or more children)

If you have a MyABDR account for two or more patients (eg, where you switch between two or more children, or a parent and a child), your first screen will be **SELECT A PATIENT**.

Choose one of the patients/children.



After selecting the patient/child, the ABDR/MyABDR Privacy Collection Notice will be displayed.



Follow the instructions from **step 4** to complete the consent form for this patient/child.

ABDR/MyABDR Privacy Consent Form – MyABDR web site January 2015

If you select CONSENT for the first patient/child, you will be returned to the **SELECT A PATIENT** screen.



You can now:

- Select the second patient/child to complete the consent form for them as well
- Or select the first patient/child and go on to record a treatment for them or product for their inventory as usual.

You will need to complete a consent form for each patient/child. The consent form will be displayed when you first select each patient/child.

4. Read the entire Privacy Collection Notice.

Make sure you continue to the bottom of the page.



The screenshot shows a web form titled "Consent To Privacy" for user "Brendan STACKER [Change]". It includes a MyABDR logo, a light blue instruction box, and a section titled "The Privacy Collection Notice was last updated on 11/12/2014". The notice text states: "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."

This is an updated version of the Privacy Collection Notice you read when you first registered for MyABDR.

The Australian national laws to protect your privacy have been made stronger.

As a result, at the end of this Notice you are now being asked formally if you consent or agree to have your personal information in the ABDR.

You may also be asked to consent on behalf of your child if they are the patient at the HTC and are under 18.

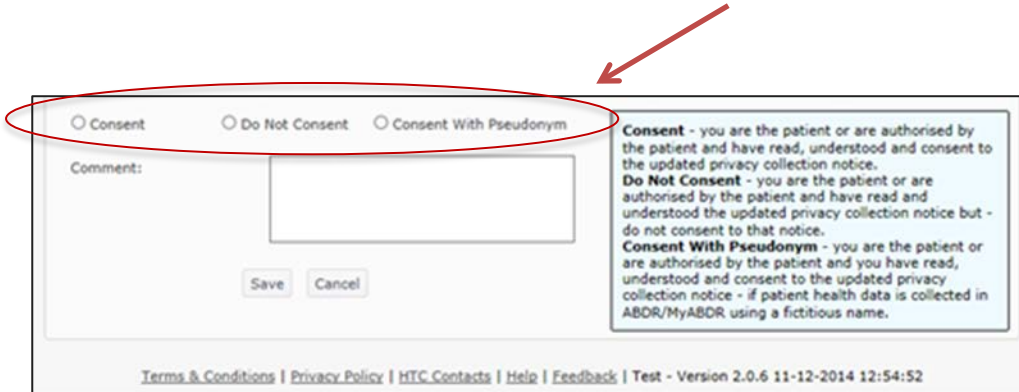
This is called an **opt-in** system.

- It will make it clear whether you have agreed to have your personal information in the ABDR.
- You also have an opportunity to find out more about the ABDR and how your personal information is used and protected

In the past it was an **opt-out** system – your personal information was kept in the ABDR unless you asked for it not to be entered in the system. You may recall your Haemophilia Treatment Centre talking to you about the ABDR and giving you a pamphlet.

5. Consenting

At the end of the Notice, you will see **three (3) options for consent**.



The screenshot shows a consent form with three radio button options: Consent, Do Not Consent, and Consent With Pseudonym. A red oval highlights these three options, and a red arrow points to the 'Consent' option. Below the options is a 'Comment:' field and 'Save' and 'Cancel' buttons. To the right, there is a text box explaining the three options. At the bottom, there is a footer with links: Terms & Conditions | Privacy Policy | HTC Contacts | Help | Feedback | Test - Version 2.0.6 11-12-2014 12:54:52.

Option 1 – CONSENT

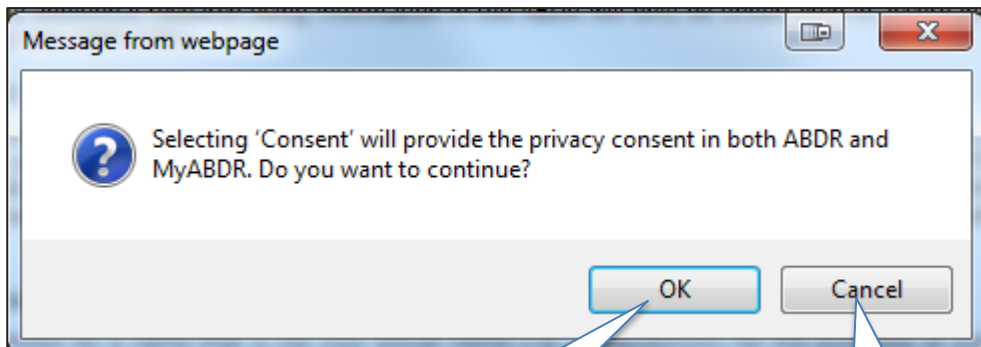
If you choose this option, it means you understand the Privacy Collection Notice and agree to have your (or your child's) personal data in the ABDR.

To select this option, **click in the circle next to Consent** and **click on SAVE**.



The screenshot shows the same consent form as above, but with the 'Consent' radio button selected (indicated by a red circle and an arrow). The 'Save' button is also highlighted with a red circle and an arrow. The 'Do Not Consent' and 'Consent With Pseudonym' options are unselected.

This message will appear:



If you **click on OK**, you will be taken to the MyABDR home screen where you can use MyABDR as normal.

If you **click on Cancel**, you will be taken back to the Consent to Privacy screen

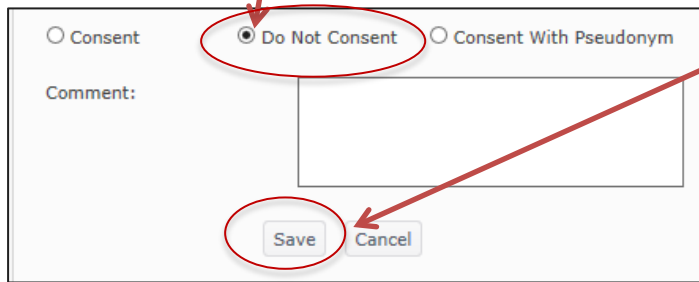
Option 2 - Do Not Consent

This means you understand the Privacy Collection Notice and do not want your (or your child's) personal data in the ABDR.

Choosing this option will mean that the Haemophilia Treatment Centre (HTC) cannot enter data about you (or your child, if they are the patient) in the ABDR. You will no longer be able to use MyABDR.

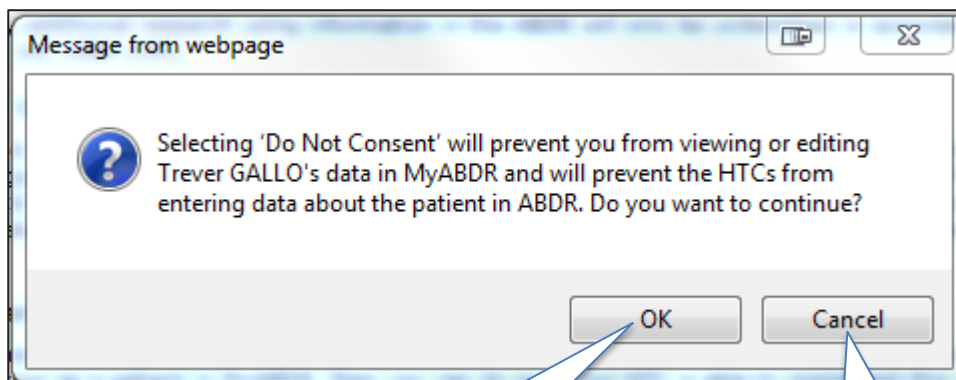
A decision not to consent will not impact on treatment but your doctors and haemophilia treatment team will need to make different arrangements to access your (or your child's) latest medical records. It would be valuable to discuss this with your HTC first before choosing this option.

To select this option, **click in the circle next to Do Not Consent** and **click on SAVE**.



The screenshot shows a web form with three radio button options: 'Consent', 'Do Not Consent', and 'Consent With Pseudonym'. The 'Do Not Consent' option is selected and circled in red. Below the options is a 'Comment:' field. At the bottom of the form are two buttons: 'Save' and 'Cancel'. The 'Save' button is also circled in red. A red arrow points from the 'Save' button back to the 'Do Not Consent' option.

A message confirming your choice will appear, eg:



If you **click on OK**, you will be taken to the MyABDR login screen. You will no longer be able to use MyABDR for this patient (eg, you or your child).


If you **click on Cancel**, you will be taken back to the Consent to Privacy screen

Option 3 - Consent With Pseudonym

This means you understand the Privacy Collection Notice and agree to have your (or your child's) personal data in the ABDR, but under a different made-up name.

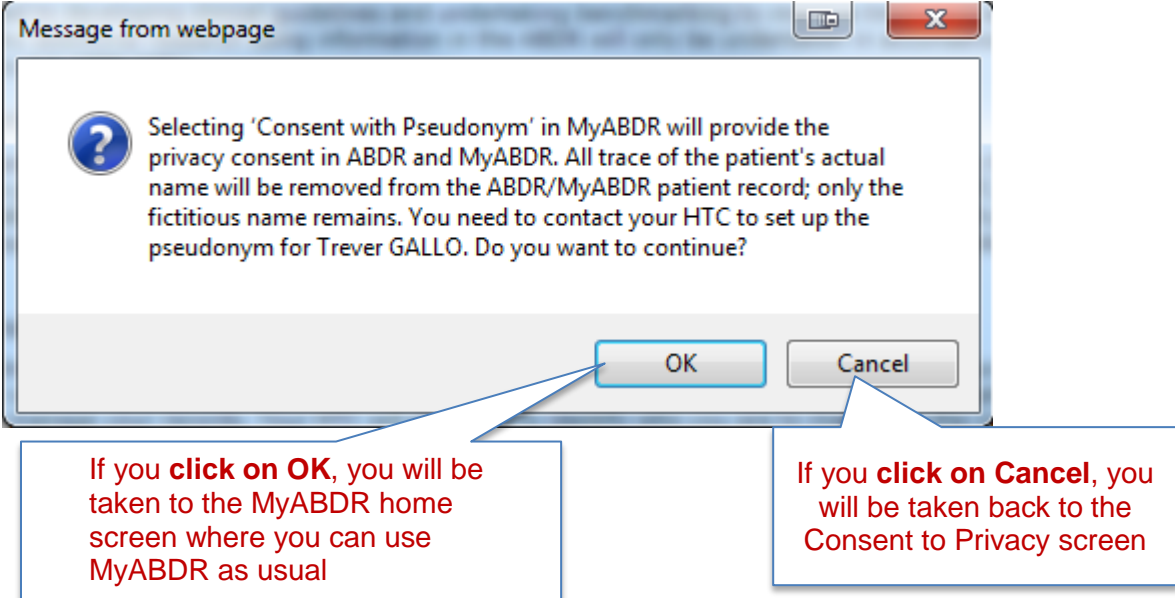
Choosing this option will send a message to the HTC requesting this option. You will need to contact the HTC to see whether they are able to set up a pseudonym and still properly manage your patient records. You will also need to discuss how this would work in situations such as care in other hospitals or health care settings or in emergencies.

To select this option, **click in the circle next to Consent With Pseudonym** and **click on SAVE**.



The screenshot shows a web form with three radio button options: 'Consent', 'Do Not Consent', and 'Consent With Pseudonym'. The 'Consent With Pseudonym' option is selected and circled in red. Below the options is a text area labeled 'Comment:'. At the bottom of the form are two buttons: 'Save' and 'Cancel'. The 'Save' button is also circled in red. Red arrows point from the text above to the 'Consent With Pseudonym' option and the 'Save' button.

A message confirming your choice will appear, eg:



The screenshot shows a message dialog box titled 'Message from webpage'. The message text reads: 'Selecting 'Consent with Pseudonym' in MyABDR will provide the privacy consent in ABDR and MyABDR. All trace of the patient's actual name will be removed from the ABDR/MyABDR patient record; only the fictitious name remains. You need to contact your HTC to set up the pseudonym for Trever GALLO. Do you want to continue?'. At the bottom of the dialog are 'OK' and 'Cancel' buttons. Two callout boxes provide instructions: one for the 'OK' button stating 'If you **click on OK**, you will be taken to the MyABDR home screen where you can use MyABDR as usual', and one for the 'Cancel' button stating 'If you **click on Cancel**, you will be taken back to the Consent to Privacy screen'.

ABDR/MyABDR Privacy Consent Form – MyABDR web site January 2015

Troubleshooting

What if I have already completed a printed ABDR/MyABDR Privacy Consent Form at my HTC?

If you have already completed a printed Consent Form at your HTC, your HTC will register your decision about consent in the ABDR at the HTC.

When your decision is registered in the ABDR, it will turn off the updated ABDR/MyABDR Collection Notice page at login.

- If you chose **Consent** or **Consent with Pseudonym** on the printed form, you will be able to use MyABDR as usual.
- If you chose **Consent with Pseudonym** on the printed form with the agreement of your HTC, your HTC will organise for the patient name that appears on the MyABDR home page after you login to be the same as your pseudonym.
- If you chose **Do Not Consent** on the printed form, your login to MyABDR will no longer work. You will not be able to enter data about the patient (you or your child) in MyABDR and the HTC will not be able to enter data about you or your child, if they are the patient, in the ABDR.

I have already completed a printed ABDR/MyABDR Privacy Consent Form at my HTC, but the Privacy Collection Notice has still appeared when I login.

If there has been a delay between you completing the form and the HTC entering your decision about consent in the ABDR, the Privacy Collection Notice will still appear when you login to MyABDR.

In this case, you can complete the online consent form with the same decision as on your printed form, and make a note that you have already completed a printed form in the COMMENT box.



Consent Do Not Consent Consent With Pseudonym

Comment:

Save Cancel

Consent - you are the patient or are authorised by the patient and have read, understood and consent to the updated privacy collection notice.
Do Not Consent - you are the patient or are authorised by the patient and have read and understood the updated privacy collection notice but - do not consent to that notice.
Consent With Pseudonym - you are the patient or are authorised by the patient and you have read, understood and consent to the updated privacy collection notice - if patient health data is collected in ABDR/MyABDR using a fictitious name.

[Terms & Conditions](#) | [Privacy Policy](#) | [HTC Contacts](#) | [Help](#) | [Feedback](#) | [Test](#) - Version 2.0.6 11-12-2014 12:54:52

ABDR/MyABDR Privacy Consent Form – MyABDR web site January 2015

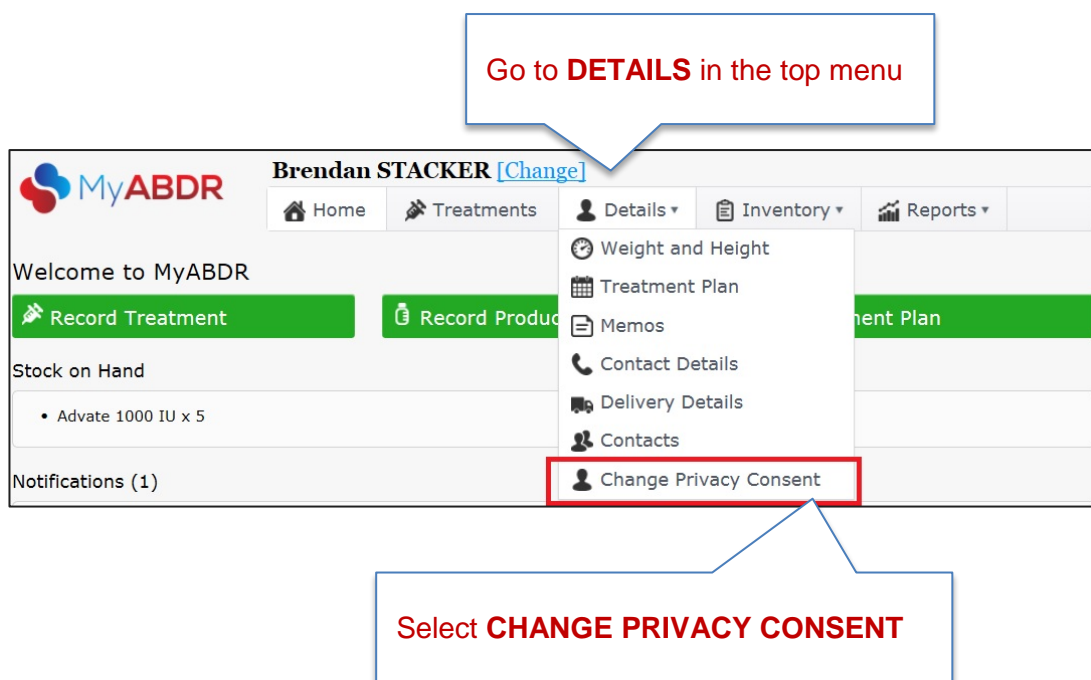
Helpdesk – call 13 000 BLOOD (13 000 25663) or email myabdr@blood.gov.au

I have already completed a ABDR/MyABDR Privacy Consent Form. What do I do if I change my mind later?

The ABDR and MyABDR are voluntary and you can choose to opt in or out at any time.

To change your ABDR and MyABDR consent status:

- If you completed a consent form at your HTC, contact your HTC directly.
- If you did not consent or consented with a pseudonym, contact your HTC directly.
- If you completed your consent on MyABDR, you can change your privacy consent status after you log into MyABDR on the web site version.



When you select **CHANGE PRIVACY CONSENT**, you will be presented with the **PRIVACY COLLECTION NOTICE**.



Consent To Privacy **Brendan STACKER** [\[Change\]](#)

Please read this notice and complete the Consent Form below before continuing to use MyABDR.

The Privacy Collection Notice was last updated on 11/12/2014

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.

Go to *step 4* for instructions on completing the consent form. (page 4)