

## Privacy consent using a pseudonym

From 26 January 2015 a new Privacy Policy will apply for the Australian Bleeding Disorder Registry (ABDR), and the MyABDR application.

Under this policy a patient (or the patient's parent, guardian or other authorised representative) will be asked to give privacy consent for the recording of information about the patient in ABDR/MyABDR. New modifications to ABDR/MyABDR will allow for this privacy consent to be recorded in the ABDR system. More information about patient privacy in ABDR and MyABDR can be found at [www.blood.gov.au/privacy-info-abdr-myabdr](http://www.blood.gov.au/privacy-info-abdr-myabdr).

The privacy consent process and system changes have been designed to allow for a patient to elect to have their information recorded against a name which is not their own legal name – that is, a pseudonym.

A pseudonym can only be set up in ABDR by a patient's Haemophilia Treatment Centre, and cannot be set up directly by the patient using the MyABDR application. Where a pseudonym is set up, the HTC is required to maintain a separate record of the pseudonym against the patient's real identify.

There are a number of important points which should be discussed between a patient and the HTC before a decision is made to elect to use a pseudonym in ABDR:

- If a pseudonym is set up in ABDR/MyABDR it will apply for all records relating to that patient ID number in the system. There will be no record of the patient's real identity in the ABDR system.
- Only one pseudonym can be used for a patient at any one time.
- Using a pseudonym will not make a patient's records in ABDR/MyABDR fully anonymous. The patient ID number in ABDR and MyABDR provides the unique identifier for the patient. The HTC must retain the ability to identify the patient with their ABDR patient ID number through the record of the pseudonym maintained separately at the HTC. The patient may also be identifiable to some extent by the particular details recorded about the patient in ABDR.
- The information about a patient recorded in ABDR/MyABDR may be used in a range of ways to assist in managing the care and treatment of the patient. If a pseudonym is used in ABDR, the information will be recorded against a different name that information held in other health records within the hospital where the HTC is located, or in the records of other health service providers or other organisations. The patient has primary responsibility for managing any possible confusion or lack of linkage between information in ABDR and information in different health records is with the patient.
- If the patient chooses to receive an ABDR patient card the name on the card will be the pseudonym entered in ABDR. There may be a risk of confusion if the card is used to indicate the patient's bleeding disorder status to an HTC or health service where the patient is not previously known, particularly in an emergency situation.
- The authority of a patient representative to apply a pseudonym to the ABDR/MyABDR record for patients they represent must be confirmed.
- The option to use a pseudonym is available to be used where it is reasonably practicable, and in some circumstances it may not be reasonably practicable for a particular patient,