

Privacy Statement and Notice

1 September 2015



This statement explains how the National Blood Authority (NBA) manages personal and sensitive information that it collects about you. The NBA is the Commonwealth Government agency responsible for the supply of blood and blood products in Australia, including immunoglobulin (Ig) products derived from human blood plasma.

The NBA is currently developing BloodSTAR (System for Tracking Authorisations and Reviews) to support the *Immunoglobulin Governance National Policy: Access to Government Funded Immunoglobulin Products in Australia*¹. BloodSTAR will replace the current paper based processes and the Blood Service's Information management system, and will be rolled out in early 2016. Information about patients approved to receive government funded immunoglobulin products that is expected to extend beyond 2015 will need to be recorded in BloodSTAR and cannot be stored without your explicit consent.

How your information is collected

The NBA collects your personal and sensitive information from organisations or persons who provide healthcare products or services such as doctors, nurses, hospitals and pathology laboratories.

What information will be collected?

The information collected about you will include identification details such as your name, date of birth, sex, and may include your individual health identifier (IHI), hospital identifiers and sensitive health information.

Purpose of collection

Why is my personal and sensitive information collected?

Ig products are a precious and high cost resource. Government policy requires that government funded Ig products can only be approved for specific medical conditions. Accordingly, the primary purpose for collecting your information is to correctly identify you and to assess your eligibility to receive these products. It will also help your doctor or nurse to quickly access reliable information about your continuing eligibility.

As a secondary purpose, summary level grouped information which does not identify you, is also important for:

- ◆ identifying priorities for research
- ◆ prescriber education and training
- ◆ performance evaluation and improvement of the supply, authorisation and use of immunoglobulin products

- ◆ further developing the Criteria upon which government policy is based
- ◆ supply planning so the NBA can make sure enough Ig products are available to meet patients' needs
- ◆ enabling reporting on the program for supply, authorisation and use of government funded immunoglobulin products.

Any additional research will only be undertaken in line with the requirements of the *Privacy Act 1988* (Cth) and any relevant laws. The data may only be made available for research if it has a properly constituted human research ethics committee (HREC) approval.

How long will my information be kept for?

Patient records will be retained for a minimum period of 20 years in line with the requirements of the *Archives Act 1983* (Cth) and the National Pathology Accreditation Advisory Council (NPAAC) requirements (laboratory accreditation).

¹ National Blood Authority, Immunoglobulin Governance National Policy: Access to Government Funded Immunoglobulin Products in Australia, November 2014, (www.blood.gov.au/Ig-program)

Can I choose not to provide consent or be included in BloodSTAR?

Yes. However, your doctor will not be able to submit your personal information to enable assessment of your eligibility and you will therefore not be able to receive government funded Ig products. Alternative arrangements are available, including Jurisdictional Direct Order or Private Order and should be discussed with your doctor. For more information visit: <http://www.blood.gov.au/lg-publications>

Who will access my personal information?

Only authorised users involved directly or indirectly in your treatment via a secure log in. These include: your doctor, nurse, laboratory staff, pharmacy staff, Authorisers (specified staff at the Blood Service) and NBA staff that provide technical and user support.

How can I be confident that my personal information is protected?

The NBA uses a security protected system with strict rules around access. We will also not pass on your personal information to anyone without your consent, unless the law requires us to do so. These procedures protect your information from unauthorised access, interference, alteration, disclosure, loss or misuse.

Do I have to use my name in BloodSTAR?

Yes. Your name and personal details are used to uniquely identify you to ensure that you receive the appropriate treatment. Pseudonym and anonymity will not be possible as these cannot be reliably cross checked with hospital processes and may potentially put you or other patients at risk of not receiving appropriate treatment.

Can I access and correct my personal information?

Yes, you can do this in line with privacy laws. Contact your doctor in the first instance. If you are unhappy with the response you receive, you can contact the NBA at privacy@blood.gov.au, the privacy commissioner or equivalent in your State or Territory, or the Australian Privacy Commissioner.

How long is my consent to collection of my information valid for?

Your initial consent to the collection, use and disclosure of your personal information will remain valid unless you withdraw it. This applies whether such information is used for the primary purpose or for the secondary purpose.

If I have changed my mind, how do I opt out of BloodSTAR?

You can withdraw your consent by contacting your doctor. From that point on, no further details about you will be collected. Information already recorded in your individual patient record will not be deleted but will be retained for historical reporting purposes. However ongoing access to government funded Ig products will cease. Alternative arrangements are available, including Jurisdictional Direct Order or Private Order and should be discussed with your doctor. For more information visit: <http://www.blood.gov.au/lg-publications>

If I have withdrawn my consent can I change my mind and opt back in to BloodSTAR?

If you withdraw your consent to BloodSTAR, you may at a later date choose to reactivate your patient record by providing consent again.

NBA Privacy Policy

The privacy policy gives more details on how the NBA manages personal information generally and how you can make a privacy complaint to the NBA. A copy of the policy can be found at <http://www.blood.gov.au/privacy>

Contact us

If you have any questions in relation to this information or require more information, please contact the Health Provider Engagement Team on 13 000 BLOOD (25663) or email: support@blood.gov.au

² Criteria for the clinical use of intravenous immunoglobulin, Second Edition (July 2012), COAG Health Council (www.blood.gov.au/ivig-criteria).