What is the Australian Blood Donor Study (ABDS)?
Several blood services around the world, such as in Denmark, the Netherlands, and Finland, have done large studies involving blood donors. These studies are making important contributions, particularly around improving donation safety for blood donors and strengthening transfusion safety and supply systems. Australian Red Cross Lifeblood is planning to start a similar study here in Australia, but first we want to find out whether it is feasible in our context, and whether blood donors in Australia would participate.

Our study, the Australian Blood Donor Study (ABDS) will help with blood donation and transfusion policies, ensuring continuous supply of highly effective blood and blood products, and improving population health outcomes in Australia. For the first part of the study (pilot phase), we’re collecting information related to your lifestyle, health, and blood donation through a survey. We would also like to know whether you would take part in any future studies that require providing a broader consent for collection of blood samples and linking the survey information with external health records (like hospitalisation records).

In future studies, if we were to take a blood sample with broader consent, these would be stored and may be used for ethical approved research to improve donation and transfusion safety. These research may include genetic testing of your blood. When we do a genetic test on a blood sample, we look at patterns in a person’s DNA. Some of these patterns might help us to learn whether there could be an association between blood donation and donor health.

Please note that at this time we’re not asking for your consent to provide blood samples for research or follow up of your health through external health records; we’re simply asking your willingness to provide consent if asked in future.

Can I participate?
Given blood in the last 12 months? Congratulations! You’re eligible for the study.

What does it involve?
- If you’d like to participate in this research please visit our study webpage donateblood.com.au/abds and scroll down to the section asking you to take the survey. Instructions on how to complete the survey will be provided at the beginning. The survey will take about 15 minutes to complete.
- When completing the online questionnaire, please enter your Donor ID, which you can find at the top of the letter you received.

Are there any risks?
What about benefits?
There are no foreseeable risks, and we don’t expect you to experience any discomfort. There are no immediate benefits to you after filling in this survey, but there are plenty of possible long-term benefits for others. This survey will inform us about the best way to recruit participants and improve the tools we collect data.

The full-scale ABDS may lead to improvements in donor health management as well as helping to continually ensure a safe supply of blood and blood products for patients in need.

How is the research project being managed and funded?
We’re funding the study as part of our regular research budget. It’s being conducted by our own researchers in collaboration with researchers from University of New South Wales (UNSW), University of Technology Sydney (UTS), the University of Sydney, and Sanquin (the Netherlands blood service). Lifeblood will manage the data collection to keep it safe.
How do we keep your data safe and secure?

Safety and security of your data is our top priority. The research data will be stored securely in a password protected file on a secure Lifeblood server that can only be accessed by the lead investigator and investigators approved by the Australian Red Cross Lifeblood Ethics Committee.

How will we protect your privacy and confidentiality?

We comply with the Privacy Act 1988 so any information obtained in connection with this study that could identify you will remain confidential and will only be disclosed with your permission or as required by law. The information you provide will be linked to your routine data collected by Lifeblood. We’ll take out all your identifying information before the researchers analyse the data. We plan to publish the results in academic journals and Lifeblood internal reports, but you won’t be identified in any publication. The investigators will take all reasonable measures to ensure the confidentiality of your records.

Your consent

Participation in this study is voluntary. You’re under no obligation and a decision not to participate won’t affect your future relationship with Lifeblood in any way. If you decide to get involved in this study now, you’re free to withdraw your consent and stop at any time later without prejudice. If you choose to withdraw, any information regarding your involvement in the study will be removed and destroyed. To withdraw from the study please call the study information line on 02 9234 2515 or email abds@redcrossblood.org.au.

Ethics approval and contact information

This research project has been approved by the Australian Red Cross Lifeblood Human Research Ethics Committee. If you have any concerns or complaints about the manner in which this research is being conducted, please contact the Australian Red Cross Lifeblood Ethics Committee Secretary by calling 02 9234 2368, emailing ethics@redcrossblood.org.au or writing to 17 O’Riordan Street, Alexandria, NSW, 2015.

If you have any questions about the study, please feel free to contact Dr Surendra Karki (call 02 9234 2552 or email abds@redcrossblood.org.au). We’re happy to answer any additional questions you have in the future. This information sheet is for you to keep.
Please read the following statements:

1. I freely agree to participate in the research study as described in the Participant Information Sheet.
2. I’ve read the Participant Information Sheet and understood it.
3. I’ve had the opportunity to ask any questions and am satisfied with the answers I’ve received.
4. I understand that my participation is voluntary and that I’m under no obligation to participate and a decision not to participate will not in any way affect my relationship with Australian Red Cross Lifeblood.
5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
6. I understand that if I have any questions relating to my participation in this research, I may contact Dr Surendra Karki by phone 02 9234 2515 or by email abds@redcrossblood.org.au.
7. I have been given a copy of this Consent Form and the Participant Information Sheet to keep.
8. I give permission for the researchers to use my existing data collected by Australian Red Cross Lifeblood in conjunction with information provided in this questionnaire for scientific research.
9. We may need to contact you in future for follow-up research. You can decide then whether or not you’d like to participate.

By completing and returning this consent form and the questionnaire to researchers, I consent to participate in this study. I understand all of the points above and that my information will be kept strictly confidential and will be used for scientific research only. Reports and publication arising from the study will be based on de-identified information only and will never disclose my identity.

My participation is entirely voluntary. I understand that I can withdraw from the study at any time by calling the study helpline on 02 9234 2515 or emailing abds@redcrossblood.org.au. If I withdraw, any information about me collected for this study will be permanently deleted.

If you have any concerns or complaints about the manner in which this research is being conducted please contact the Lifeblood Ethics Committee Secretary by phone on 02 9234 2368, facsimile on 02 9234 2411, emailing Ethics@redcrossblood.org.au or writing to 17 O’Riordan Street, Alexandria, NSW, 2015.