

The real-world
PROBE study is
now available!



PROBE FOR REAL-WORLD EVIDENCE

WHY IS THE PROBE STUDY IMPORTANT?

What is the impact of haemophilia and treatment on Australians? How can we have access to high quality evidence about this?

With new treatments becoming available this kind of evidence is particularly important. We need to be able to explain what it's like to have haemophilia and the impact of different types of treatments. HFA's advocacy relies on credible data. Without this data we have not had enough strong evidence to use in our advocacy for new treatments.

We also need good evidence to understand the different experiences of living with haemophilia – for example, women with haemophilia or who carry the gene, people with mild, moderate or severe haemophilia or inhibitors, getting older with haemophilia.

The **PROBE (Patient Reported Outcomes Burdens and Experiences)** study is a great opportunity for our community to give this evidence.

WHAT IS PROBE?

PROBE is a multi-national research study (www.probestudy.org) which allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. It compares their answers to other people in their community who do not have a bleeding disorder.

You may have done the PROBE survey in the past. This was a test survey. In 2015 Australia joined more than 20 other national haemophilia organisations around the world to successfully test and validate the questionnaire.

The international PROBE team is led by well-respected haemophilia organisation and academic investigators.

This time the PROBE study is collecting real-world evidence. Statistics from Australians who complete the questionnaire will be provided to HFA by the international team for us to use in our advocacy and planning for the future.

HOW CAN YOU HELP?

You are invited to complete the questionnaire if you are an **adult (18 years+) who lives in Australia** and:

- Have haemophilia or carry the gene

OR

- Do NOT have a bleeding disorder.

You may also like to pass the survey on to your partner/ wife/husband or other members of your family or interested friends. If they don't have a bleeding disorder, their answers are also very valuable – the study needs equal numbers of people affected by haemophilia and people without a bleeding disorder.

We need a few hundred Australian participants for good quality results, so the more people who complete the survey, the better!

HOW TO DO THE SURVEY

The questionnaire is available:

- Online at <https://plus.mcmaster.ca/PROBE/>
- Or ask your local Foundation or HFA for a print survey pack



WHAT HAPPENS TO YOUR DATA?

All responses are anonymous. They are combined for statistical data and will not identify individuals. All responses are treated confidentially. The survey is voluntary – it is up to you if you want to complete it and no one will know if you have or haven't.

TEST SURVEY

You may be aware that in May 2019 Australia was accidentally sent the test website to distribute for the PROBE real-world survey. The international team realised and acted very quickly to fix this. Links on the HFA website and our covering letter have now been corrected to the final website for PROBE - <https://plus.mcmaster.ca/PROBE/>. If you completed the survey on the test website, don't worry - the international team has transferred your data to the real-world website. People visiting the test website now will receive a pop-up directing them to the real-world survey website. The data security is the same - it's just a different database.

We have had a very enthusiastic response so far from the community. Our thanks to the many people who have already completed the real-world PROBE questionnaire in 2019!

MORE INFORMATION

For more information about the PROBE study in Australia, visit

www.haemophilia.org.au/research

Or contact Suzanne at HFA:

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PROBE

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