

PROBE Australia Study



The 2023 round of the PROBE Australia Study has now commenced!

WHY IS THE PROBE STUDY IMPORTANT?

What is the impact of haemophilia on Australians? What has changed since new treatments became available? How can we provide high quality evidence about this?

With more new treatments becoming available, HFA's advocacy will rely on strong and credible data.

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

You may have done the PROBE survey in 2019. This is a new round of the survey.

The 2023 round will compare results now to 2019, which was before new treatments were widely available in Australia.

WHAT IS PROBE?

PROBE (Patient Reported Outcomes Burdens and Experiences) is a multi-national and well-respected 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.

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.**

Consider passing the survey on to your partner/wife/husband or other members of your family or interested friends or colleagues. We need several hundred Australian participants for good quality results.

HOW TO DO THE SURVEY

The questionnaire is available:

- **Web version** at myprobe.org
- Or download the **myPROBE app** from Apple Store or Google Play (Android)
- Or ask **your local Foundation** or **HFA** for a **print survey pack**

Choose **Country-Australia** and **Language-English** and **CONTINUE**

The web and app survey automatically saves your responses as you go. You can come back later and keep going from where you left off.

WHAT HAPPENS TO YOUR DATA?

All responses are anonymous and confidential. They are combined for statistical data and will not identify individuals. The survey is voluntary – completely up to you.

Statistics from Australians survey responses are provided to HFA by the international PROBE team to use in our advocacy and planning for the future. You may have seen the 2019 data in the HFA Getting Older report.

MORE INFORMATION

For more information about the **PROBE Australia study**, visit: www.haemophilia.org.au/research

Or contact Suzanne at HFA:
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