

Why is PROBE important?

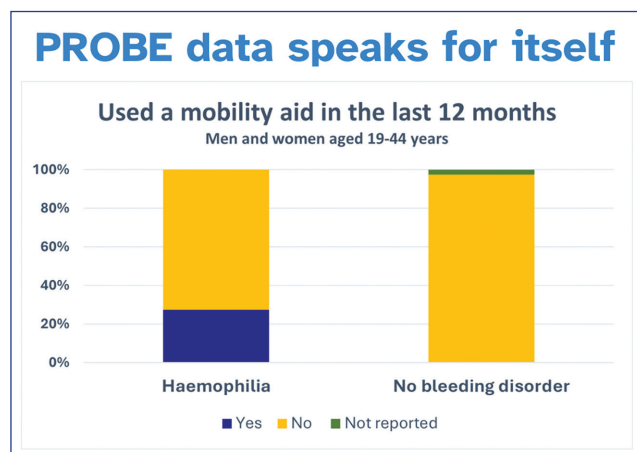


HFA is building evidence about the needs of men and women affected by haemophilia in Australia and we would really appreciate your help.

WHAT IS THE PROBE STUDY?

The **PROBE Australia Study** is co-ordinated by Haemophilia Foundation Australia and is an internationally recognised and validated questionnaire. It collects data on the impact of haemophilia on the quality of life of both men and women who are affected, either because they have haemophilia or carry the gene. It compares their experience to people who do not have a bleeding disorder.

So far we have only had around 150 men and women complete the PROBE survey – we need at least 400 for good data.



WHAT DO WE DO WITH THE DATA?

PROBE data is high quality and credible and we use it in many ways. You may have seen some of the data from the 2019 PROBE Australia Study in reports and conference presentations. Some examples include:

- Advocacy to government about new treatments and services
- The HFA Getting Older report, about issues with physical function and pain, mild haemophilia, women, hepatitis C

- The plenary on mild haemophilia at the 2023 Australian Conference
- International meetings to discuss the issues for people with mild haemophilia
- The HFA poster on 2019 PROBE data at the 2024 WFH Congress (a peer-reviewed publication).

HOW CAN YOU HELP?

Please consider completing the current PROBE Australia survey as soon as possible – and you don't need to have a bleeding disorder to contribute!

If you don't have a bleeding disorder, you can be a health professional, or someone interested in haemophilia. The comparison group is a slice of the Australian general community.

PROBE is voluntary and anonymous, so it is up to you – but we would really value your support.

Who can complete the survey?

Adult (18 yrs+) men and women living in Australia

- Who have haemophilia/carry the gene
- OR who do NOT have a bleeding disorder (comparison group)

How to do the survey

It's very easy! Go to:

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

If you have already done the survey, perhaps you could share it with family and friends and encourage them to complete it too.

QUESTIONS?

Visit www.haemophilia.org.au/probe-australia-study

Or contact Suzanne at HFA:

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