

PROBE STUDY PHASE 2 RESULTS



How can HFA have access to good quality data about the treatment and health experiences of Australians with bleeding disorders? This is crucial to help HFA understand current issues for our community, and to quantify and represent these issues to governments or treatment and service funding bodies in a credible way.

PROBE (Patient Reported Outcomes Burdens and Experiences) is a multi-national study on the impact of living with a bleeding disorder, treatment outcomes and quality of life. HFA has joined other haemophilia organisations around the world to participate in this study and build a collection of robust patient-reported data. Each country will have access to statistical information collected from study participants in their own country and will be able to compare this data to the rest of their region or other regions around the world. The research will support efforts to improve treatment and comprehensive care programs in Australia and other countries around the world.

Phase 1 and 2 of the PROBE study tested a survey in people with haemophilia. The survey allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life.

PHASE 2

Phase 2 of the PROBE study tested:

- Whether the survey questions would capture consistent responses if they were repeated twice in the same community (e.g. Australia)
- The stability of the online survey

Australia conducted two rounds of the survey between 20 September 2016 and 22 February 2017.

Survey participants were welcome to complete both rounds. Participants lived in Australia, and were:

- Adults (18 years or over) and had haemophilia or carried the gene
- Or were the partner, family member or caregiver of someone with a bleeding disorder, but did not have a bleeding disorder themselves (controls).

Australian survey participants for phase 2:

People with haemophilia/carry the gene – 51 (required = 50)

People without a bleeding disorder – 52 (required = 50)

TOTAL – 103 (required = 100)

21 countries participated.

RESULTS

An important learning from this phase was that larger numbers of survey participants will be needed at a

country level to provide meaningful data. Participants were grouped as controls and into haemophilia severity, eg mild/moderate/severe. When comparing the different groups of participants, the sample sizes were found to be too small for stable results at a country level, but could be demonstrated at a regional level – for Australia, this was the Western Pacific Region and included countries such as Japan, Vietnam, Australia and New Zealand.

The results validating the PROBE study at a regional level were presented at the International Society on Thrombosis & Haemophilia (ISTH) Scientific and Standardization Committee (SSC) meeting in 2018 and are available on the PROBE study website – www.probestudy.org.¹

Feedback about the online survey and its stability has been used to fix bugs and make enhancements for the phase 3 version.

DASHBOARD

The international team have set up a simple and user-friendly dashboard to display the country and region data for the participating national haemophilia organisations. Testing the dashboard and providing feedback was an exciting time for us as we realised the great potential of this data for HFA – both to understand the issues for our community and represent them in a meaningful way to funding bodies and decision-makers.

PHASE 3

Phase 3 is planned to begin at the end of 2018. It is the final stage of implementing the study around the world, and will be collecting real world data to measure the impact of haemophilia and treatment.

This will be Australia's opportunity to collect current data about the experience of our community. As you can see, it will be important to gather as many survey responses as possible. Surveys will be available in print and online. Stay tuned for more information!

For more information about the PROBE study in Australia, visit the PROBE section on the HFA website - www.haemophilia.org.au/research/probe-study.

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REFERENCES

1. Chai-Adisaksopha C, Noone D, Curtis R, et al. PB189: Exploring regional variations in the cross-cultural, international implementation of the Patient Reported Outcomes Burdens and Experience (PROBE) study. Abstracts of the 64th Annual Meeting of the Scientific Standardization Committee of the International Society on Thrombosis and Haemostasis, July 18–21, 2018. In Research and Practice in Thrombosis and Haemostasis July 2018;2:1-368. <doi:10.1002/rth2.12125.>