

WHAT HAVE WE LEARNED FROM PROBE?

Suzanne O'Callaghan

If you saw the PROBE data about ageing and haemophilia in the HFA Getting Older report, you may have wondered if similar results are found internationally.

Intrigued by the early results from Australia, the international PROBE investigators analysed the PROBE data at a global level and found some strong correlations. Their conclusions? Aging is associated with a steeper decrease in health status and health related quality of life in people with haemophilia than in people who do not have a bleeding disorder. In people with haemophilia, this decrease is large enough to be identified and measured every 10 years from the age of 18 years. The results were published in a poster at the ISTH 2020 Virtual Congress.¹

PROBE (Patient Reported Outcomes Burdens and Experiences) is a multinational validated study where Australians can give evidence about the impact of living with haemophilia and of different sorts of treatment on their bleeds, pain, activities of daily living and quality of life. There is also a comparison group of people who do not have a bleeding disorder. The PROBE questionnaire includes different sets of questions to measure health-related quality of life: specific haemophilia-related questions (the PROBE score), the EQ-5D-5L utility index, and the EuroQol visual analog scale (EQ-VAS) of global health. Interestingly, the international study also found that the PROBE score is more sensitive than the EQ-5D in measuring the association of ageing on the specific domains (eg, physical, psychological, social) that were measured in both people with haemophilia and people who do not have a bleeding disorder.

HOW CAN YOU BE PART OF PROBE?

As you can see from the Getting Older report, the PROBE study is a very important source of data to help HFA to better understand current issues - and this data will be crucial for our treatment advocacy.

Have you already completed the PROBE questionnaire? If not, please take a moment to consider making your contribution to the data. The more responses we have, the more robust our data will be and the more questions we will be able to answer. At the moment, we still need more people on prophylaxis to complete the survey for solid data on the different types of treatment. But we would be keen to hear from everyone!



PROBE
Patient Reported Outcomes Burdens and Experiences Study

**YOUR EXPERIENCES
WILL MAKE
THE DIFFERENCE**

You are invited to complete the survey if:

- you are an adult with haemophilia or carry the gene
- or you are an adult and DON'T have a bleeding disorder (as a comparison group)

The survey is available at
<https://tinyurl.com/PROBE-Australia>

Or ask HFA or your Foundation for a print copy

ANY QUESTIONS?

For more information about PROBE in Australia, visit
www.haemophilia.org.au/research/probe-study

Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173

REFERENCE

1. Germini F, O'Callaghan S, Chai-Adisaksopha C, Curtis R, Frick N, Nichol M, Noone D, O'Mahony B, Page D, Stonebraker J, Skinner M, Iorio A, PROBE investigators. Association between ageing and health status in persons leaving [living] with hemophilia and controls without a bleeding disorder – Insights from the PROBE Study. [abstract] Research and Practice in Thrombosis and Haemostasis. 2020; 4 (Suppl 1). < <https://abstracts.isth.org/abstract/association-between-ageing-and-health-status-in-persons-leaving-with-hemophilia-and-controls-without-a-bleeding-disorder-insights-from-the-probe-study/>>.