

# Research studies: why participate?



Image: Cottonbro for Pexels.com

You may have noticed that you are being invited to participate in quite a few research studies at the moment.

One reason for this is that there are several new treatments for bleeding disorders currently going through the process to become available in Australia. As part of this process there are studies underway to understand:

- ❖ the impact on people with bleeding disorders
- ❖ patient preferences
- ❖ to prepare the resources to support new treatment products – this includes ‘Australianising’ the language for questionnaires as well as support products and services
- ❖ how to improve treatment and care.

There are also other studies to understand the impact of a bleeding disorder, for example, on joints and muscles, where the aim is to improve health outcomes.

**It can be hard to find the time when you are busy, but this is your opportunity to have a say about your experience and what you would like - now and in the future.**

**In Australia decisions about health services, treatment and care are strongly influenced by research in the area.**

HFA will draw your attention to some research studies via e-news and social media as they become available.

**We strongly encourage you to look at them and consider if you would be able to participate.**

## WHERE TO FIND CURRENT STUDIES?

HFA has a standard process to review research studies before promoting them.

Links to reviewed studies are in the **PARTICIPATING IN RESEARCH** section on the HFA website - <https://tinyurl.com/HFA-research-participating> .



There are three different categories of research:

- ❖ **Clinical research** – studies testing the impact of health conditions on the body and treatments, how well they work and how safe they are.
- ❖ **Market research** – studies evaluating people’s preferences and experiences of treatment and care, products and services.
- ❖ **Social research** – studies about people’s experiences to better understand how to improve their health and wellbeing.

HFA also occasionally conducts our own community surveys and research studies, such as the PROBE Australia Study. These are to help with representing people with bleeding disorders in Australia and with providing relevant education and programs.

You will find information about HFA studies under **RESEARCH** or in the **NEWS** items on the HFA website ([www.haemophilia.org.au](http://www.haemophilia.org.au))

Any questions? Contact Suzanne O’Callaghan, HFA Policy Research and Education Manager on [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) or P: 1800 807 173.