

Getting Older Community Survey 2019

Participant information sheet



HAEMOPHILIA FOUNDATION AUSTRALIA

HFA study number: HFA/GOP/NA/3

HFA study team

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You are invited to take part in this study. Please read this information sheet in full before you decide whether to participate. If you would like more information about this study, please feel free to contact the HFA study team via the telephone numbers and email addresses above.

About this study

Haemophilia Foundation Australia (HFA) invites you to participate in a national study to help identify the range of needs people with bleeding disorders and their partner/family or friends/carers may have as they grow older.

Haemophilia Foundation Australia (HFA) is committed to supporting active, independent and fulfilling lives for people in our bleeding disorders community. **Getting Older** is a priority project of HFA. This survey is to help HFA with strategic planning, advocacy, support and education and as a result may benefit you and others in the bleeding disorders community in the future.

In this survey you will be asked personal questions about work/retirement, housing, finances, aspirations for the future, information and education, computer and mobile device use, support, and social connectedness. The survey is voluntary, anonymous and confidential. It is not for collecting health statistics or identifying personal information.

The survey takes approximately 20 - 30 minutes.

You can complete the survey in print (on paper) or online.

To complete the online survey, go to <https://www.surveymonkey.com/r/GOPsurvey2019>

If you do the survey online, your answers will save automatically as you go until you submit so you can return to complete it later, even if you close the browser.

Who is this survey for?

This survey is intended for:

- **People with bleeding disorders who are getting older**
- **Their partners/family or friends/carers**

To complete this survey you will need to be 18 years or over and an Australian resident.

This survey is voluntary and confidential.

This survey is completely anonymous and your participation is voluntary.

You do not have to complete the survey if you don't want to. No one will ever know if you have completed the survey or not and it will not affect your relationship with your Haemophilia Foundation or Haemophilia Treatment Centre. You can skip any questions without an asterisk if you don't want to answer them. If you start the online survey and then change your mind, you can close your browser at any time, and no more data will be collected from you after this point. However, because the survey is anonymous, you will not be able to withdraw any of the answers you have already given.

Your answers to the survey will be treated confidentially.

If you accidentally write something identifying, HFA will remove it before we share the results with any third parties. Any information we show to government or any other agencies will not identify individuals but will explain the impacts of getting older with a bleeding disorder and the sorts of needs this community has. However, to protect your privacy, we recommend that you do not write anything identifying in your answers.

The survey uses the US-based SurveyMonkey website to collect the data. The survey data is collected with 'anonymous' settings and identifying data such as IP address is not collected. Only aggregated results, where answers are grouped rather than individual, will be downloaded from SurveyMonkey. The results will be stored confidentially and securely on the SurveyMonkey website as well as in private and secure storage at HFA for 20 years, when it will be destroyed.

For more information on the SurveyMonkey data protection and privacy policy, visit <https://www.surveymonkey.com/mp/legal/privacy-policy/>.

What are the risks?

Answering questions in this survey may make you realise you need more information about your health, treatment or particular services.

Who can help you with this?

- The haematologist (specialist doctor) or others in the haemophilia team at your local Haemophilia Treatment Centre. They may also be able to refer you to appropriate services
- Your usual doctor or other health professionals if you don't attend a Haemophilia Treatment Centre
- You may also find useful information at the following websites:
<https://www.haemophilia.org.au>
<https://www.myagedcare.gov.au>
<https://www.ndis.gov.au/>

You may also find it raises questions or sensitive issues for you that you want to discuss further.

Who can help you with this?

- The Haemophilia Social Worker, Psychologist or Counsellor at your Haemophilia Treatment Centre (HTC)
- A counsellor or someone else you can trust. Your HTC or your GP can give you a referral if you need one
- Lifeline – ph 13 11 14.

Costs

There are no costs to you to participate in this survey. If you complete the print survey, you can use the reply-paid envelope or address provided to return the survey through the post and you will not have to pay for postage.

Survey results

The survey results will form part of the HFA Getting Older needs assessment report, which will be published on the HFA website. The results may also be presented in other formats, eg, conference presentations or posters. A summary of the results will also be published in the HFA quarterly magazine, *National Haemophilia*, and on the HFA website. If you would like to go on the mailing list for *National Haemophilia*, contact HFA on hfaust@haemophilia.org.au or 1800 807 173 or sign up for the HFA email newsletter on the HFA website - www.haemophilia.org.au.

Consent

Completing and submitting this survey online or returning the print survey in the reply paid envelope will be taken as indicating that you consent to participate in this needs assessment consultation.

Disability and Interpreting services

If you need help to do the survey, these services may be of assistance:

National Relay Service (TTY) – for people who are deaf or have a hearing or speech impairment and wish to use a proxy to complete the survey for them or to speak to the Project Officer about the survey:

<https://www.dss.gov.au/contact/national-relay-service>

Helpdesk: Ph 1800 555 660; TTY: 1800 555 630; SMS: 0416 001 350

Translating and Interpreting Service (TIS):

<https://www.tisnational.gov.au>

General Inquiries - 1300 655 820

More information and advice

You are welcome to contact Preetha Jayaram, Getting Older Project Officer at Haemophilia Foundation Australia to discuss this project further, or if you need help doing this survey.

T: 1800 807 173

E: pjayaram@haemophilia.org.au

If you have any questions or concerns about the Getting Older project, please contact Sharon Caris, Executive Director, Haemophilia Foundation Australia.

T: 1800 807 173

E: scaris@haemophilia.org.au

Ethics approval and complaints

The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the *National Statement on Ethical Conduct in Human Research (2007)* – incorporating all updates. This Statement has been developed to protect the interests of people who agree to participate in human research studies.

If you have any concerns or complaints about the conduct of this study, you are welcome to contact the Operations Manager, Bellberry Limited on 08 8361 3222.