

# 4. Methodology



The HFA Getting Older needs assessment was a 12 month project to identify, understand and respond to the range of needs Australian people with bleeding disorders may have as they grow older, and help find appropriate solutions for them and their partner, family or carers.

Both qualitative and quantitative data was collected relating to:

- Lived experience and preferences of older people with bleeding disorders and their partners, family or carers
- Professional expertise of expert health professionals, researchers and other relevant agencies.

## 4.1 Scoping phase

As an initial scoping phase, HFA conducted some preliminary interviews and discussions with a sample of the range of stakeholders and members of the Advisory Group. A set of open-ended questions for interviews was tested and refined. HFA also developed a table of emerging issues, constructed from the data arising from interviews, and this formed the basis of further consultation with Haemophilia Treatment Centre health professionals and discussion with the HFA Getting Older Project Advisory Group.

## 4.2 National consultation

The scoping phase was followed by more in-depth national consultation, consisting of:

- Interviews with affected community members, partners and family members
- Interviews with health professionals, Foundation staff, and other organisations with a common interest

- Community forums
- The HFA Getting Older Community Survey
- Age-related data from the PROBE Australia study
- Further information and comment from the HFA Getting Older Project Advisory Group
- Responses from state and territory Haemophilia Foundations about priorities for their older community members and their partners/family.

## 4.3 Interviews

The HFA Getting Older Project Officer conducted face-to-face and telephone interviews nationally with:

- older people with bleeding disorders
- partners and family members
- Haemophilia Treatment Centre health professionals
- National and state/territory Foundation staff, other organisations with a common interest in chronic health conditions, and a peer support worker.

Interviews were conducted during March 2019 to January 2020 with participants from the Australian Capital Territory, New South Wales, Queensland, South Australia, Victoria and Western Australia.

The interviews used interview question schedules developed during the scoping phase and tailored for each group.

- Questions for community members covered aspirations and plans for getting older, current and future concerns, personal and external supports, any HIV- or hepatitis C-specific issues, what would help both individual and their partner/family and how they could help others.
- Questions for health professionals, Foundations and other organisations asked at what age a person with a bleeding disorder might be said to be 'ageing' and what emerging issues they were seeing in relation to getting older.

Interviews were transcribed and analysed by theme.

## 4.4 Community forums

Bleeding disorder community forums were conducted in the Australian Capital Territory (ACT) and Queensland (QLD) in June and July 2019. Older people with bleeding disorders and their partners and family were invited to take part, with forum discussion activities over a casual meal. The forums were conducted by the HFA Getting Older Project Officer and supported by the local haemophilia social worker or counsellor and the local Haemophilia Foundation. Questions were based on a simplified version of the community member interview schedule.

The forums were well-attended:

- 10 community members participated in the ACT
- 18 community members participated in QLD.

Discussions from the forums were recorded, transcribed and analysed by theme.

## 4.5 Getting Older Community Survey

The **HFA Getting Older Community Survey** was an anonymous questionnaire for people with bleeding disorders in Australia who are getting older and their partners, family and carers. It was available in print and online, using the SurveyMonkey platform.

The survey was developed specifically as a consultation tool for the HFA Getting Older needs assessment. It had been noted that most of the interviews and community forums were conducted with community members who were well-connected to HFA or their local Foundation. This survey was intended to reach a broader range of bleeding disorders community members nationally to collect a wider sample of information and strengthen the evidence base.

Questions covered:

- Work/retirement, finances, aspirations and planning for the future, support and social connectedness
- Needs and preferences around information and education, peer support, computer use and online and social media platforms.

Ethics approval was received through the Bellberry Human Research Ethics Committee on 30 October 2019.

HFA did not have ethics approval to recruit participants through Haemophilia Treatment Centres and so community networks were used to distribute the survey. The intention was to reach those who are in outer suburban and regional and rural areas, those with other bleeding disorders as well as haemophilia, and those less engaged as well as those who are the most active in the local haemophilia foundations. Information on TTY and interpreting services and an invitation to contact the Getting Older Project Officer to discuss help with completing the survey were provided in the participant information sheet to encourage independent completion of the survey.

The survey was mailed to community members on HFA and local Foundation mailing lists with a covering letter from the HFA President and in some cases from the local Foundation President. The online version was promoted through HFA and local Foundation e-news, newsletters and social media and on the HFA website to reach those who are active online and may not participate regularly in face-to-face foundation activities.

Partners, families and friends were also targeted with the survey. Bleeding disorders occur in families and HFA experience is that some members of a family or a partner or friend may be more connected to a haemophilia foundation than the person with the bleeding disorder and will pass on communications to them, provide peer education to them and advocate for them. Survey promotion aimed to use a 'snowball sampling' technique, using this group to reach those who are less connected and also encouraging them to complete the survey themselves.

Surveys were distributed and responses collected during November and December 2019.

## 4.6 PROBE Australia study

Age-related data from the **PROBE (Patient Reported Outcomes Burdens and Experiences) Australia study** were also analysed to inform the needs assessment. This is a multi-national validated community questionnaire to understand the impact of haemophilia and treatment on quality of life including number of bleeds, pain, mobility, activities of daily living and related surgical interventions, including the EQ-5D measure. In Australia participation is fully anonymized. It is available online and in print.

HFA leads the PROBE study in Australia and commenced implementation of the 'real-world' data collection phase in May 2019. As with the community survey, the PROBE questionnaire was promoted and distributed through HFA and local Foundation communication networks. Only a small number of print copies were distributed, usually on request. It was also promoted at community events, such as camps and the national bleeding disorders conference in October 2019.

From January 2020 de-identified Australia results were provided to HFA by the international PROBE team via a secure online dashboard, with regular data updates. The age-related data in the Getting Older needs assessment were sourced from the February 2020 update.

The lead investigators from the international PROBE group obtained ethics approval from McMaster University, Hamilton, Canada, which houses the study database. Ethics approval in Australia was provided by Monash University Human Research Ethics Committee. Monash University has been involved pro bono in ethics oversight for the Australian testing and implementation of this study.

## 4.7 Privacy

As the consultation for the Getting Older needs assessment asked sensitive questions about individuals' personal health information, relationships and financial status, privacy considerations were very high for HFA. Moreover, apart from discrimination related to their haemophilia, many in the bleeding disorders community in this age group have experienced a traumatic level of discrimination relating to the HIV and hepatitis C epidemics and are extremely private and careful about their personal health information. An important part of the information provided to community members before participating covered how their privacy would be protected.

Interviewees were consented for participation and their consent forms, interview recordings and transcripts stored in password-protected and locked storage on the secure HFA server or at the HFA office. Data from the interviews was de-identified before analysis.

Both the Getting Older Community Survey and the PROBE Australia study were developed to enable respondents to participate anonymously. Survey questions did not ask for identifying information. Print surveys were returned in uncoded reply paid envelopes and stored in locked storage at the HFA office. The Community Survey and PROBE study both used completely anonymized survey platforms, where not even the IP address was collected. We were unaware of any identifying information in the survey responses, but as a precaution any data that could potentially be identifying was de-identified before analysis.

## 4.8 Limitations

As HFA did not have ethics approval to use HTC mailing lists for distribution of the Getting Older Community Survey and the PROBE study, promotion and distribution was limited to community networks. As a result, this limited the extent of the bleeding disorders community HFA was able to reach with the consultation. HFA identified a number of barriers for people with bleeding disorders to participate, including frailty, disability, physical and mental capacity, literacy and limited English language skills, along with lack of engagement with haemophilia foundations and their communication networks. HFA had taken this into account with the Community Survey, encouraging partners, family and carers to complete the survey if the older person was unable to undertake the survey or not engaged. Local foundations drew the survey to the attention of some families with perceived barriers and they were also invited to use interpreting and TTY services or to contact the Project Officer for help with completing the survey, but this would probably only occur if they were highly motivated. HFA also used popular social media channels such as Facebook and Instagram to promote the survey to supporters who may then encourage relevant older people to participate, but this was limited by the reach of the social media posts and how engaged supporters were with the cause.

The timeframe for the Community Survey was also relatively short and limited the ability of foundations and supporters to reach out to people who were less engaged or might need more support to complete the survey.