

Preetha Jayaram is the HFA Getting Older Project Officer

GETTING OLDER PROJECT UPDATE

Preetha Jayaram



GETTING OLDER NEEDS ASSESSMENT

We have reached the final stage of the **Getting Older Needs Assessment**. This is a key part of the HFA Getting Older project. The project aims to identify, understand and respond to the range of needs people with bleeding disorders may have as they grow older, and help find appropriate solutions for them and their partner/family or friends/carers. It reflects HFA's commitment to supporting active, independent and fulfilling lives for people in our bleeding disorders community and you will see this in the types of recommendations and solutions proposed.

The HFA Getting Older needs assessment uses an 'evidence-informed' approach – it recognises that lived experience, expertise relating to clinical practice and evidence from current research each have a role to play in identifying and exploring the full range of issues. We started by scoping out the issues with some initial interviews and other consultation and then extended the project across Australia. We collected data using interviews with community and health professionals, holding community forums, and meeting with other agencies working in related areas. We also collated age-related data from the Patient Reported Outcomes of Burdens and Experiences Study (PROBE) study.

The scoping also identified the need for a wider engagement with the community – beyond those we could interview or who completed the PROBE questionnaire - and so we developed an anonymous community survey to collect national data. This was our way to hear from the wider bleeding disorders community about what is needed and the strategies and services that would help with getting older.

The project also involved establishing a national Consumer Focus Group to develop and test digital solutions for peer support and education. The Focus Group met in November 2019 and has given some valuable and creative ideas and feedback. They will continue to be involved in the development of solutions, such as the Getting Older Information Hub.

The Getting Older Project has had a great response from the bleeding disorders community nationally. To those who gave their time to participate in our Getting Older face-to-face and telephone interviews, forums, the

community survey and the PROBE study, and the focus group, I thank you individually for your unfailing support. This is new territory for the bleeding disorders community and your contributions have been invaluable.

We are currently finalising the needs assessment report. Look out for the summary in the June issue of *National Haemophilia*. The full report will be available in print and downloadable from the HFA website.

INFO HUB

As a first step in our digital solutions, we have been working on an online information hub for the HFA website with resources on getting older with a bleeding disorder and peer support options. The information hub will grow and develop over time as we explore the issues raised in the needs assessment. It is currently being designed with the assistance of the HFA Getting Older Focus Group and will be available soon – watch this space!

WHAT'S NEXT?

The Getting Older needs assessment report will include recommendations, including areas to explore further. The aim is to start a discussion both the community and health care providers about where to go next with the recommendations and to look at ways to achieve them. We would value your input and you will have opportunities to provide more comments and suggestions.

My role in the Getting Older Project was a 12-month position and is now drawing to a close. Being involved as the Project Officer in HFA's Getting Older Project has been a unique opportunity in my career history. I thank you individually for sharing your stories with me and giving me a wealth of knowledge and life experiences to take away.

ANY QUESTIONS?

If you have any questions about the Getting Older Project or needs assessment report, please contact Suzanne at HFA

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