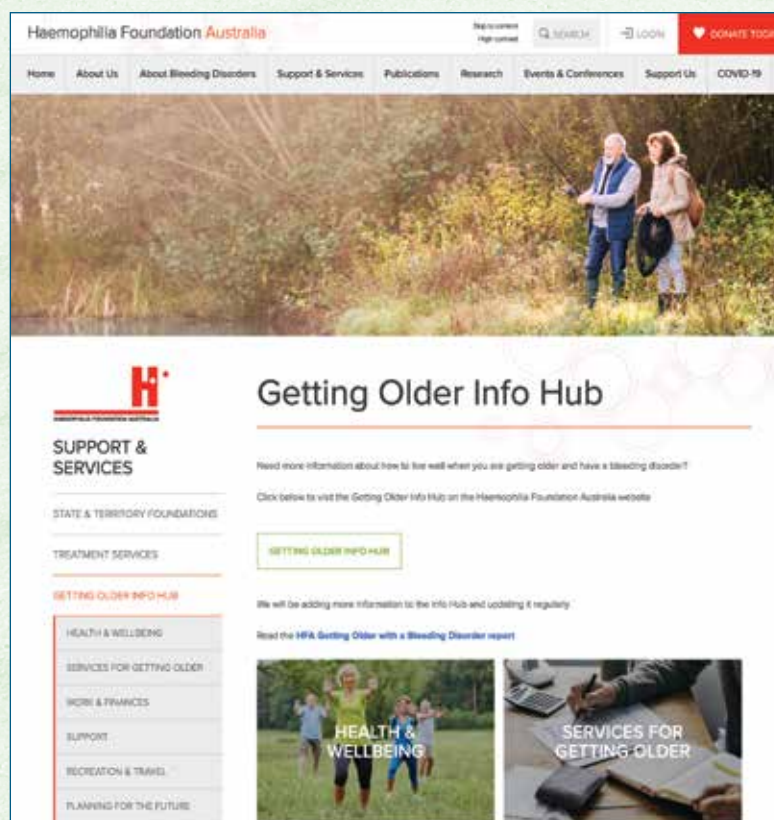




Getting Older Info Hub survey

Suzanne O'Callaghan



What does our community think of the HFA Getting Older Info Hub? What do you like? How could it be improved?

The Getting Older Info Hub was a key outcome of our Getting Older report and we needed to know if it was hitting the mark, so in October and November 2021 we held a community survey. What did people say? The results are below.

WHO COMPLETED THE SURVEY?

41 people (**19 female/22 male**) completed the survey

They came from all states and territories except ACT; 1 did not say where they lived

66% were 55 years and over

76% had haemophilia or carried the gene, 17% had VWD, others had rare clotting factor deficiencies, inherited platelet function disorders or acquired haemophilia.

WHAT DID THEY THINK OF THE INFO HUB?

- 83%** thought it was extremely or very easy to use
- 63%** thought it was extremely or very useful
- 66%** thought the design was excellent or very good.

WHAT DID THEY LIKE?

- Informative and useful, updatable
- Clear, concise, easy to navigate
- Relates to older people like me, real people talking about their conditions
- Personal experiences, tips and videos
- Well researched but in layman's language.

WHAT COULD BE IMPROVED?

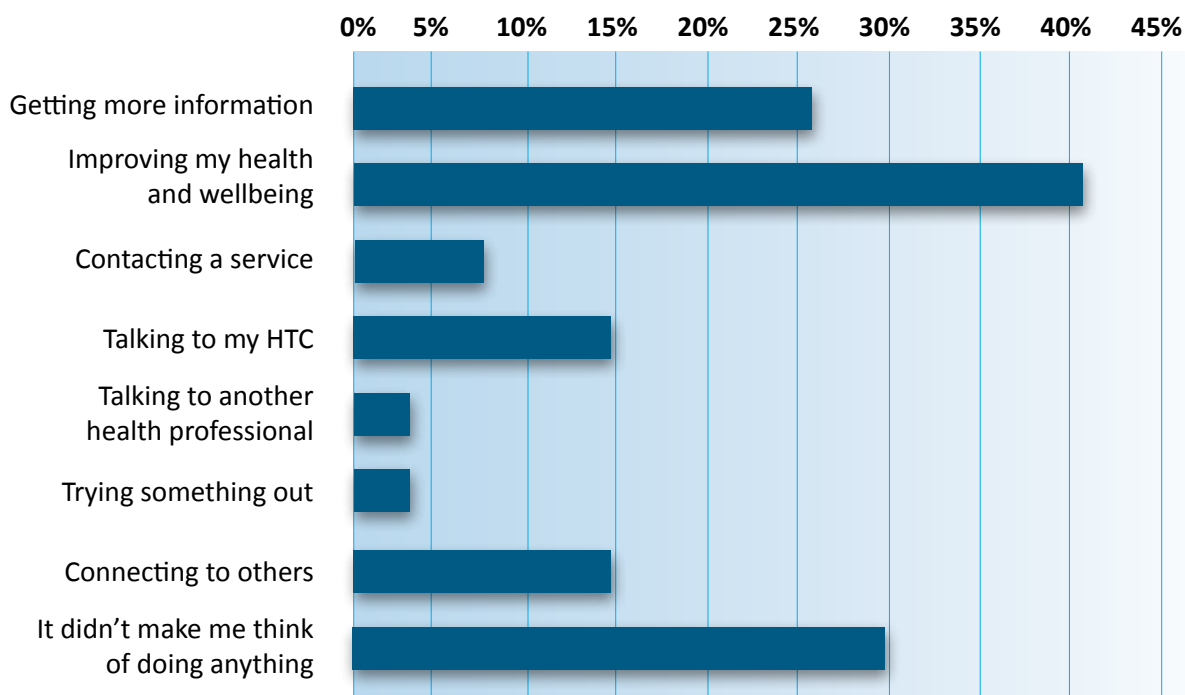
- There is already a lot of good information on the Info Hub
- More on how bleeding disorders affect us as we age – skin, arteries, hypertension, mobility, new treatments, surgery, mild haemophilia, research into VWD and ageing
- More on the common health conditions of ageing and using a GP
- More personal stories
- Keep updating; homepage to draw attention to new information or activities/events
- More life-affirming, dynamic/interactive information – light-hearted, inviting people to check page regularly.

WHAT DID THEY DO WITH THE INFORMATION?

- 81%** strongly agreed or agreed that **after visiting the Info Hub they knew more about getting older, services and support**

Did visiting the Getting Older Info Hub make you think about doing something?

Tick all that apply



COMMENTS AND SUGGESTIONS

'A lot of information - all in the one place!'

'Clear concise correct information that you can trust is so important.'

'It just doesn't have that WOW factor.'

'It is a great initiative. For obvious reasons, much info is directed to children and now we are living longer, there needs to be more info re older living with haemophilia.'

'It is a collated area with lots of important relevant information for aging haemophiliacs. Instead of trying to find all of the information myself, it is presented there with no digging required.'

'Easy to access and to navigate around the site. It has real people talking about their conditions.'

'Older people talking about treatment before it became easier, the joint damage and viruses, that it is not just me.'

'Maybe some lighthearted topics, such as "things to do with the grandkids that don't require much physical activity". Include something that would get people to bookmark and visit the page on a regular basis like an interactive recipe hub or weekly puzzles.'

'Made me reflect - feel old - sad - seeking someone to talk to is important.'

'Made me think about contacting my HTC about worsening joint damage and planning for surgical options in the future. Also to talk to my employer about a more ergonomic setup for me at work (office) to avoid my joints locking/ becoming stiff.'

WHERE TO NEXT?

It was very helpful to hear from community members about the topics where they would like more information and that they would like more personal stories. We have added them to our content development schedule.

We took very seriously the comments about needing a more dynamic and life-affirming look and feel and content on the Info Hub. The concept of the Info Hub is about living well into the future as you grow older and the structure, images and topics on the Info Hub

will need to promote this. We are already looking into some options, both in the short term and the longer term. More soon!

Our thanks to everyone who completed the survey.

Visit the Getting Older Info Hub at
www.haemophilia.org.au/getting-older

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Rare Disease Day 2022

Rare Disease Day is celebrated worldwide on 28 February to raise awareness about the experiences of people with rare diseases.

The 2022 theme of **Rare is many. Rare is strong. Rare is proud** reminds us how important it is to come together and connect as a community. This is an opportunity to share personal stories and acknowledge the challenges for our community members who live with a rare disorder.

WHAT IS A RARE DISEASE?

In Australia, a disease is considered rare if it affects less than 5 in 10,000 people.

Around 8% of Australians (2 million people) live with a rare disease.

About 80% of rare diseases are genetic.¹

Haemophilia is considered rare.