

Suzanne O'Callaghan is HFA Policy Research and Education Manager

# The Female Factors survey 2019

Suzanne O'Callaghan

In July 2019 HFA undertook an evaluation survey of our two latest **The Female Factors** booklets, *Female Factors - information for young women with bleeding disorders* and *Telling others about bleeding disorders*. We are working on the next **The Female Factors** resources and wanted to have feedback on the booklets we have published and what improvements to make in the future.

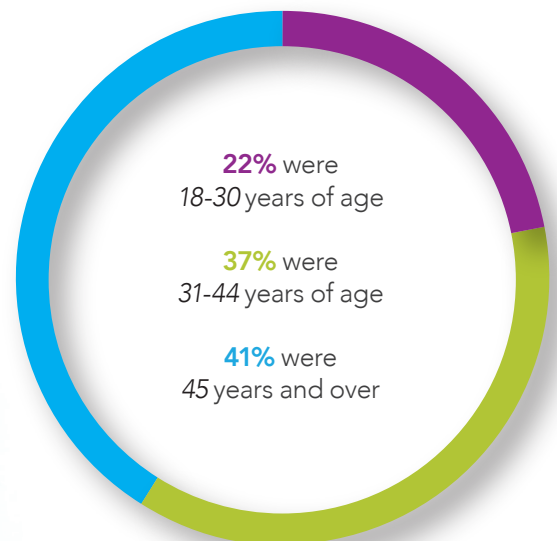
**The Female Factors** is the HFA women and girls project. The project is developing specific information resources for Australian women and girls affected by bleeding disorders to:

- Increase their understanding of their bleeding disorder, treatments and strategies to manage it
- Help them to feel more connected with each other by sharing personal stories and tips with others in similar situations
- Develop high quality, evidence-based information that they can show to other doctors, nurses, dentists, physiotherapists, etc who provide their care.

## WHO COMPLETED THE SURVEY?

27 women completed the survey.

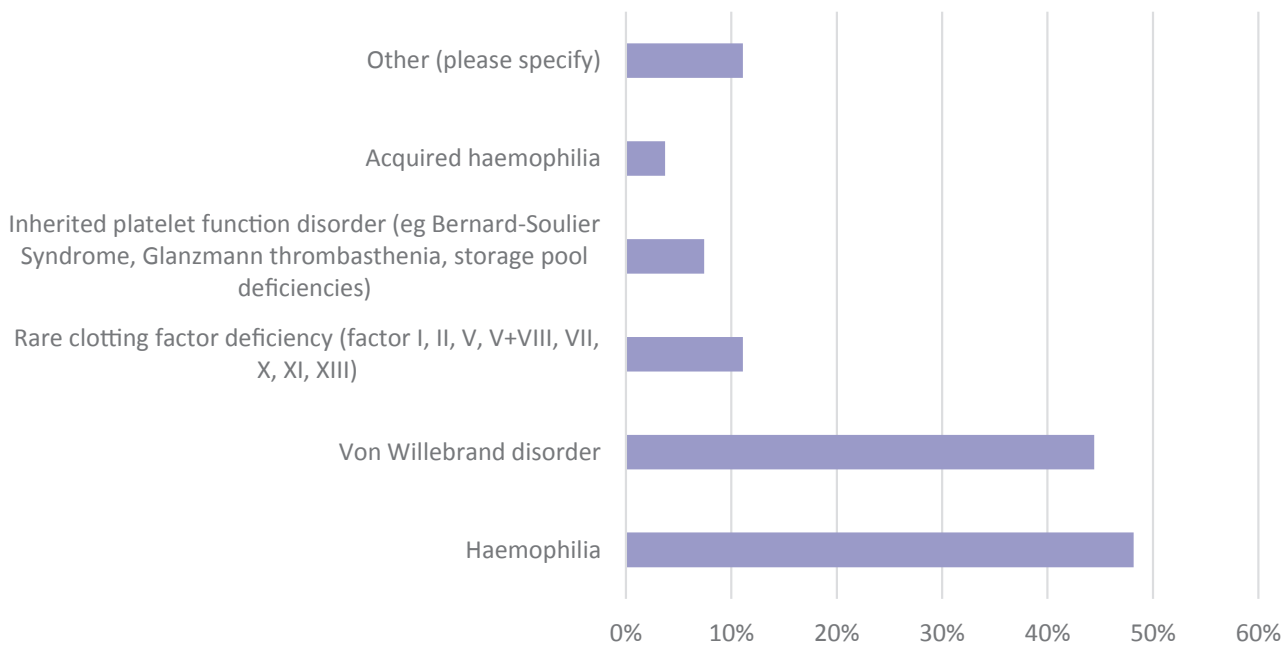
They were from all states and territories except South Australia and Tasmania (2 did not disclose where they lived).



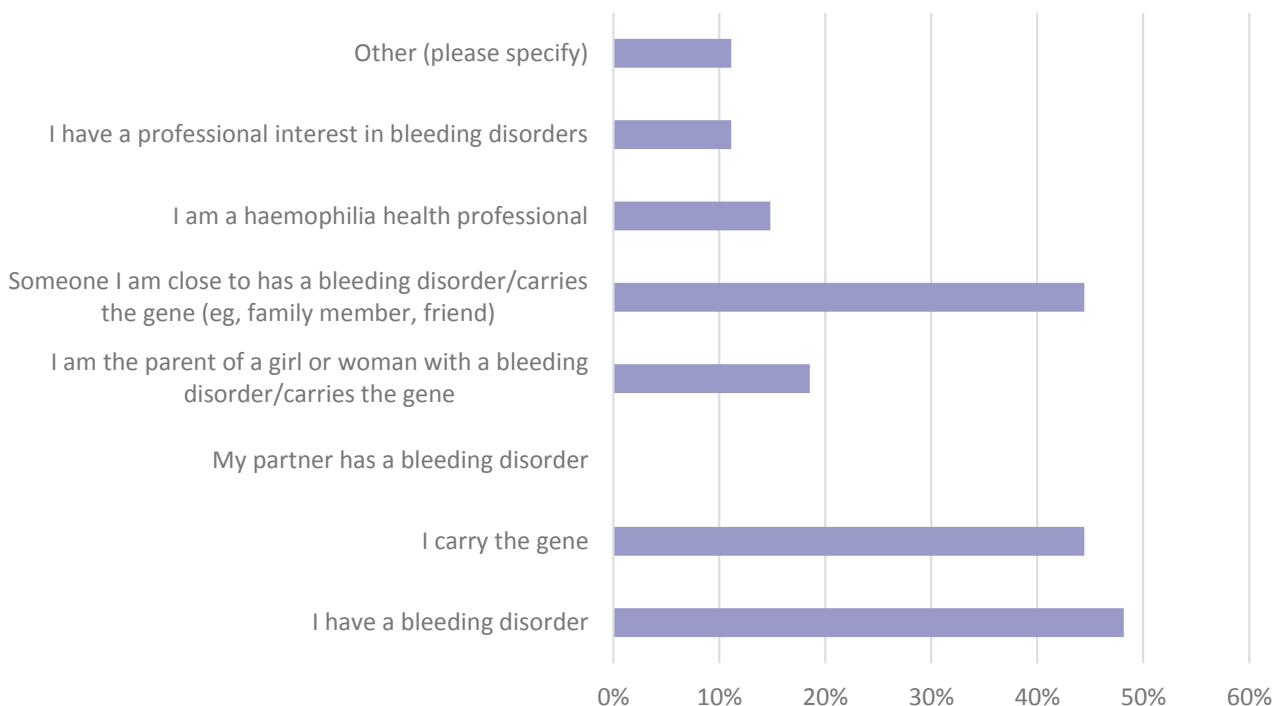
WHO COMPLETED THE SURVEY



Bleeding disorder that applies to your situation



Please tick all the statements that apply to your situation



>>



- Information about bleeding disorders in females for young women
- Working with HTC's and other health care practitioners
- Personal stories



- Issues and strategies for telling others about your or your daughter's bleeding disorder
- Disclosure and protecting your privacy
- Personal stories

## WHAT DID THEY THINK OF THE BOOKLETS?

92% had seen *Female Factors: for young women*

60% had seen *Telling others*

72% had seen the *print* version

60% had seen the *website* version

28% had seen the *online PDF* version

87% thought they were *very or extremely useful*

100% thought the *design and layout* was *very good or excellent*

### What did they like?

- Lots of useful information, easy to read
- Design was contemporary, inviting, relaxed and colourful
- Engaging for the reader

### Suggestions for improvement

- More information about women who are symptomatic, treatment for heavy periods
- More information on preparing for puberty
- Keep publishing updates.

*'Think they're great.'*

*'Easy to read small sections meant I could absorb info more easily than long walls of text.'*

*'Topics previously avoided were addressed head on.'*

*'The front cover was inviting and the stories were great to read and not too long.'*

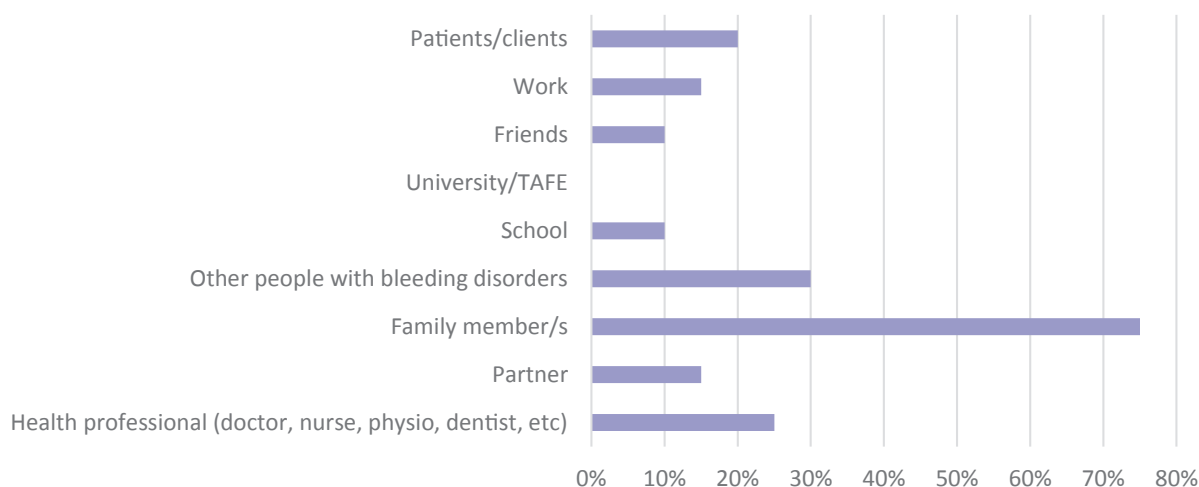
*'Perhaps more information about women with haemophilia who are symptomatic to help address the stereotype that women can't have haemophilia.'*

100%  
thought the design  
and layout was very  
good or excellent

## WHAT DID THEY DO WITH THE BOOKLETS?

**72%** passed booklets on or showed them to others

If yes, who did you pass it on/show it to?



### Why?

*'To inform and reassure.'*

*'I knew some answers to questions were in there. I also hoped they were a good resource for them to share with their friends. I knew I could rely on it being a trustworthy source.'*

*'I was excited that there are new and relevant resources relating to my bleeding disorder and hoped others would learn from them too.'*

*'Informative for colleagues who have less knowledge on these disorders.'*

*'My daughter has just found out she is a carrier and my mother is a known carrier.'*

*'It was really good, gave it to my niece's parents (her dad has haemophilia and she is also a carrier).'*

### What was the impact for them?

*'Great comments from young women about the information.'*

*'It's nice having a resource that helps explain things to others.'*

*'My husband feels much more informed about things that affect our daughter.'*

*'It's validated how I have felt for a while.'*

*'To know I'm not alone and we want more answers and any new info.'*

*'More confidence. Not ashamed.'*

*'Knowing there are a lot of us going through the same thing.'*

## WHAT'S NEXT?

HFA is working on the next two resources for The Female Factors project:

- Haemophilia diagnosis – factor level and genetic testing
- Family planning, pregnancy and birth.

We are using the feedback to develop the content and layout:

- Going the extra step to find out women's questions and answer them with the latest information
- Boxes with summary information
- Designed as an education tool both for women with bleeding disorders and their families and for others who are new to bleeding disorders
- Continuing to include personal stories and quotes.

Other resources in the pipeline:

- Symptoms, care and treatment, including self-management.

And we are always looking for women, teenage girls and parents of girls who are interested in contributing to the content with ideas or personal stories or reviewing drafts of the resources.

If you would like to be involved, contact Suzanne at HFA:

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