

MY LIFE WITH *haemophilia*

INSIGHTS FROM UK PATIENTS

Haemophilia, a chronic disease in which the ability of the blood to clot is severely reduced, causing the sufferer to bleed severely from even a slight injury¹, can have a huge impact on patients and their families. Seventy four people living with haemophilia in the UK took part in the **'My Life with Haemophilia'** survey, to provide an insight into their experience of living with this condition. Here is what we found:

Less than
1/4 of patients say they have the ability to live normal healthy lives²



The Greatest Challenges:²



54%

say: **Worrying about the next bleed**



53%

say: **Living with pain**



70%

say: **Avoiding physical activities**

"I would love to take part in sport again, I love keeping fit and playing in a team"



Treatment:²

68%

want to see additional types of treatments being more widely available

Awareness:²

46%

want to improve their knowledge and ability to contribute to treatment decisions

Support needs:²

67%

would like more opportunities to meet & talk to others living with haemophilia

35%

rate effectiveness as being the most important factor in their treatment

80%

called for greater understanding and wider discussion of haemophilia within the community

39%

would like more access to online support tools

The 'My Life With Haemophilia' survey interviewed 74 people between 4 and 55 years of age living with haemophilia from across the UK. 62% of the people interviewed were male and 38% female. 58% had haemophilia A, without inhibitors; 15% had haemophilia A, with inhibitors; 24% had haemophilia B, without inhibitors; and 3% had haemophilia B, with inhibitors.

This survey has been initiated, facilitated and funded by Shire.

¹ The Haemophilia Society, Haemophilia A. Available at: <http://haemophilia.org.uk/bleeding-disorders/haemophilia-a/> Last accessed May 2018.

² My Life With Haemophilia survey results. Shire data on file. C:ANPROM/UK/1426 May 2018

