The Bleeding Disorder Patient Experience Survey

The Haemophilia Society and Takeda UK Ltd

April 2021

The Bleeding Disorders Patient Experience Survey has been initiated and funded by Takeda and developed together with The Haemophilia Society.

Job code: C-ANPROM/UK/HG/0082 | Date of preparation: April 2021

Foreword

More than 36,000 men, women and children in the UK have a diagnosed rare bleeding disorder, and the number rises every year.[1] It is our mission at The Haemophilia Society to ensure that everyone affected by a rare bleeding disorder has equality of opportunity, the ability to connect with others in the community, and has the knowledge to feel empowered.

There have been lots of advances in treatment and care which have had a hugely positive impact on people with bleeding disorders and their families. But there is still more to be done.

Some of our members tell us that that they still do not have access to the full range of specialisms in the multi-disciplinary team, that they want to have a treatment which aligns with their personal goals – like being able to play sport or having treatment as infrequently as possible so that it doesn't impact on day-to-day life, and that they could use more psychological support. Beyond these individual stories, there has not been a systematic audit of patients' experience of care, treatment and support.

With this in mind, we are delighted to have partnered with Takeda to produce this first of its kind national Bleeding Disorder Patient Experience Survey. This report, which sets out the findings from the survey, will be a key resource for the rare bleeding disorders community to understand what matters most to people impacted by these conditions.

As the findings of this survey highlight, living with a rare bleeding disorder can have a significant impact on both physical and mental health. The data show that there is still some way to go to ensure that people with bleeding disorders have their treatment and care personalised to their needs and are able to access all the services they require. Now, in times where our healthcare system has seen rapid change to cope with new illnesses such as COVID-19, it is more important than ever to ensure that it is appropriately resourced to provide the best care to our community.

It is time to raise the ambitions in care and we hope that this report provides people with rare bleeding disorders and their families the assurance that their experiences are being recognised and that these findings will be valuable evidence for improvements in care. I would like to thank everyone who participated in the survey. It is because of your voices that we were able to take this important step in creating the evidence base needed for change.

That said, we must maintain the momentum of gathering patient experience information to inform improvements in care and hope to support future annual iterations of this survey. This will help to pave the way for better personalised, holistic care, so that all people with rare bleeding disorders can be supported to live the life they want to lead and achieve their personal goals.

Kate Burt – Chief Executive, The Haemophilia Society

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1. Executive summary

Rare bleeding disorders are predominantly hereditary conditions which affect the ability of the blood to form clots. People with rare bleeding disorders (PWRBD) lack the regular number of clotting factors in their blood, causing them to bleed for longer than usual both within the body and externally. Rare bleeding disorders are uncommon in the general population, affecting only around 36,0000 people in the UK.[1]

There are many rare bleeding disorders, some are rarer than others. The umbrella term of rare bleeding disorders includes Haemophilia A, Haemophilia B, Von Willebrand Disease (VWD), Acquired Haemophilia A (AHA) and a number of rarer conditions.

Haemophilia is the most common rare bleeding disorders and affects mostly men. Haemophilia A, caused by a deficiency of clotting factor VIII, accounts for around 80 per cent of cases of Haemophilia, whilst Haemophilia B is caused by a deficiency of clotting factor IX and occurs in around 20 per cent of cases. Both forms of Haemophilia can be classified as mild, moderate or severe depending on how much clotting factor is deficient from the blood. VWD is caused by a deficiency of the Von Willebrand protein to assist in the clotting process. The condition is usually milder than Haemophilia and equally prevalent among men and women. In a rare number of cases, autoimmune responses limiting the quality of factor VIII in the blood can occur in people with no genetic history of rare bleeding disorders in a condition known as Acquired Haemophilia A.

Although there is no known cure for rare bleeding disorders, people with rare bleeding disorders (PWRBD) can be given a variety of different treatments to prevent bleeds. In addition, changes to lifestyle can also minimise bleeding. Personalised treatment plans can empower PWRBD to manage their condition and enjoy an optimal quality of life.

However, a 2015 study of people living with Haemophilia found that those living with the condition in the UK reported the lowest quality of life measures in the EU5.[2] Despite advances in data collection in the UK on diagnosis, management and bleed rates, the burden and experience of PWRBD remains poorly defined.

As well as the risk of prolonged, painful and often spontaneous bleeding, rare bleeding disorders have been shown to affect mental health, lifestyle decisions and ability to carry out desired activities. Bleeding can also affect joints and muscle health and lead to permanent damage, so as well as medical treatment, other therapies including physiotherapy and mental health support are important for people with rare bleeding disorders.

To better understand the patient experience, and to bring about improvements in care for patients, The Bleeding Disorder Patient Experience Survey was initiated and funded by Takeda. It is a first of its kind national survey that has been run together with The Haemophilia Society looking at the experience of people living with bleeding disorders, from condition management to achieving personal life goals. The survey revealed new insights into the experiences of people with rare bleeding disorders and investigated quality of life and mental health as well as aspects of care, such as personalisation of treatment and access to services. This report sets out the findings of that survey.

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1.2 Key Statistics from the survey

The Bleeding Disorder Patient Experience Survey is a first of its kind national survey that has been run together with The Haemophilia Society looking at the experience of people living with bleeding disorders, from condition management to achieving personal life goals. Completed by 96 people between October 2020 and February 2021.
60% (58) of respondents had Haemophilia A, 24% (23) had Von Willebrand Disease, 13% (12) had Haemophilia B, and 3% (3) had Acquired Haemophilia.

1 in 3 people have had **difficulty being independent**

62% have had **difficulty walking**

76% have had **difficulty with physical activities and sports**

Please note that results reported are based on the number of responses to individual questions and may not represent the views of all 96 respondents

50% reported **feeling depressed** as a result of their condition

62% Reported feeling **anxious** as a result of their condition

57% have **worried about treatment**

55% have **worried about their next bleed**

59% said they **did not know who to contact to discuss any emotional concerns**

26% of respondents were **not given access to psychological support** to help with issues related to their bleeding disorders but would have liked to have had this

14% of respondents were **not offered a physiotherapy appointment** but would have liked one

Conversations with healthcare teams on **tailoring treatment** to a patient's lifestyle has produced satisfying outcomes in **100%**

Only **54%** of patients agree their **healthcare team support them** to carry out the activities they wish to

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2. Background and methodology

2.1 Background and objectives

A 2015 study of people living with Haemophilia found that those living with the condition in the UK reported the lowest quality of life measures in the EU5.[2] However, despite advances in data collection in the UK on diagnosis, management and bleed rates, the burden and experience of the condition on PWRBD themselves remains poorly defined. Without this understanding of individual experience, efforts to improve outcomes are less likely to be effective.

To address this, The Bleeding Disorder Patient Experience Survey was initiated and funded by Takeda. This is a first of its kind national survey that has been run together with The Haemophilia Society looking at the experience of people living with bleeding disorders, from condition management to achieving personal life goals. It is the hope of both Takeda UK and The Haemophilia Society that this survey is conducted annually and that, over time, the survey would become an authoritative dataset that can shape policy, inform guidelines and improve patients' lives.

2.2 Questionnaire design and development

The original questionnaire was developed and designed following detailed discussion between The Haemophilia Society, Takeda, and Quality Health.

Once the question set was agreed, the questionnaire was tested by five volunteers who were willing to fill it in and then discuss their thoughts on various aspects of the questionnaire design. This included comments on the questions and their wording; whether the answer options accurately reflected their experiences; whether there was anything missing; and whether the page layout was easy to follow. This exercise contributed towards refining the questionnaire into a finished version.

2.3 Sample

The survey was disseminated by The Haemophilia Society through their membership. Contact was made with Haemophilia patients on The Haemophilia Society mailing list as well as promotion via their social media channels.

2.4 Timescales and fieldwork

The questionnaire was agreed in October 2020 and was open for completion from 23 October 2020 until 5 February 2021 (15 weeks). It was officially launched on social media in December 2020.

2.5 Limitations

This is a first of its kind national survey that has been run together with The Haemophilia Society looking at the experience of people living with bleeding disorders, from condition management to achieving personal life goals. The timeframe of the fieldwork coincided with the COVID-19 pandemic, which may have had some confounding impact on responses, however a section on COVID-19 was included to understand the impact that COVID-19 may have had on the experience of PWRBD. There are around 36,000 people in the UK living with a bleeding disorder.[1] The total number of respondents to this survey was 96, making this a small sample size. Not all questions were applicable to each respondent and therefore we have shown the amount of people who answered each question for transparency. Due to this some questions have limited data. The outreach for respondents targeted broadly those with bleeding disorders and therefore the responses are not reflective of the proportions of the different bleeding disorder diagnoses within the population. The survey only captured responses from those with a diagnosis of Haemophilia A, Haemophilia B, Von Willebrand Disease and Acquired Haemophilia, therefore rarer bleeding disorders are not captured in this data. Any conclusions drawn in this report are based on the data gathered and the limitations of this data must be considered.

3. Results

3.1 Conventions

Percentages are rounded to the nearest whole number within each response option within this report. For this reason, the explanation given with each chart may not match exactly the figures within the chart. This is because the rounding can cause a difference to the total when adding two responses together to form a positive or negative response. The difference should only ever be no greater and no less than 2%.

3.2 Respondent characteristics

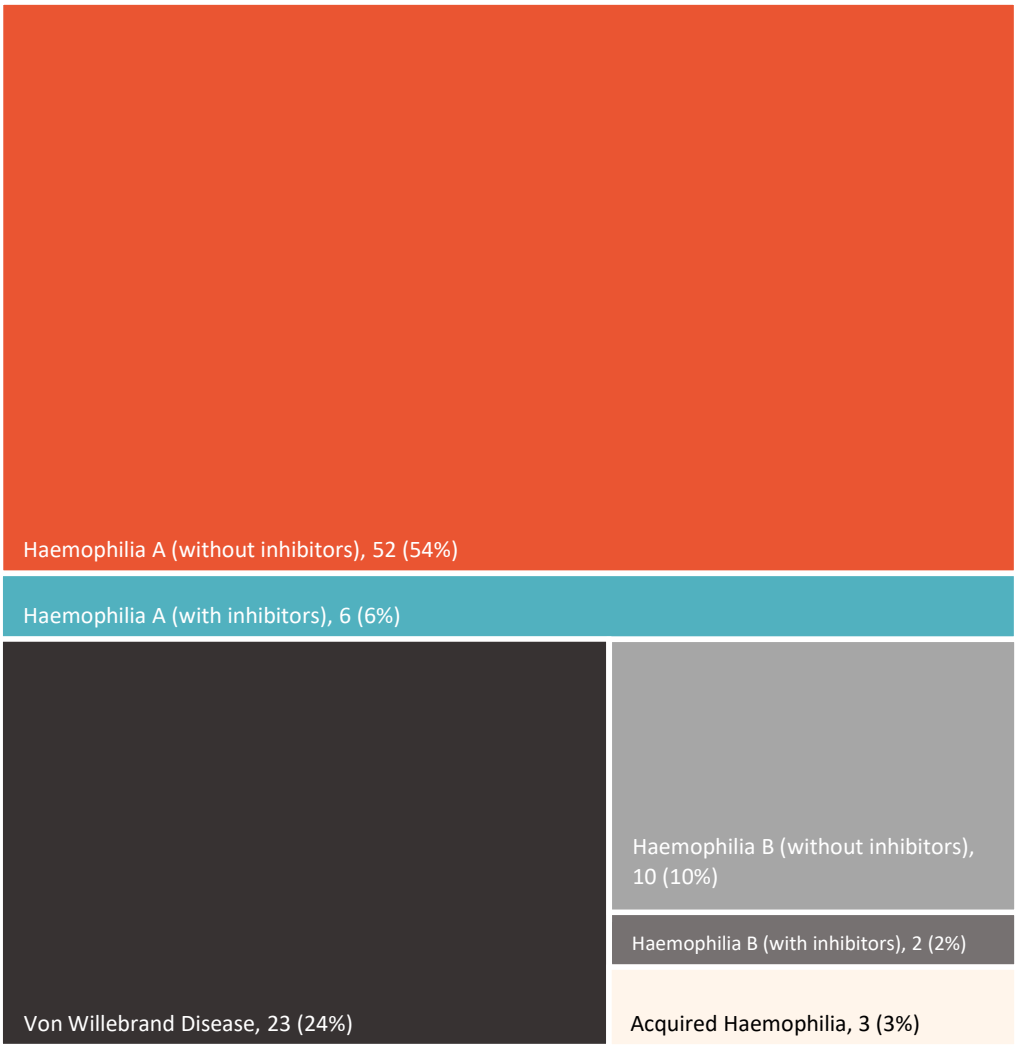
96 people completed the questionnaire.

3.2.1 Who completed the questionnaire

Most responses (86%) were completed directly by the person with the bleeding disorder. 11% of responses were made by a parent or guardian on behalf of the person with the bleeding disorder, and 2% were a joint completion between parent/guardian and the person with the bleeding disorder.

3.2.2 Bleeding disorder

60% of respondents had Haemophilia A, 24% had Von Willebrand Disease, 12% had Haemophilia B, and 3% had Acquired Haemophilia.



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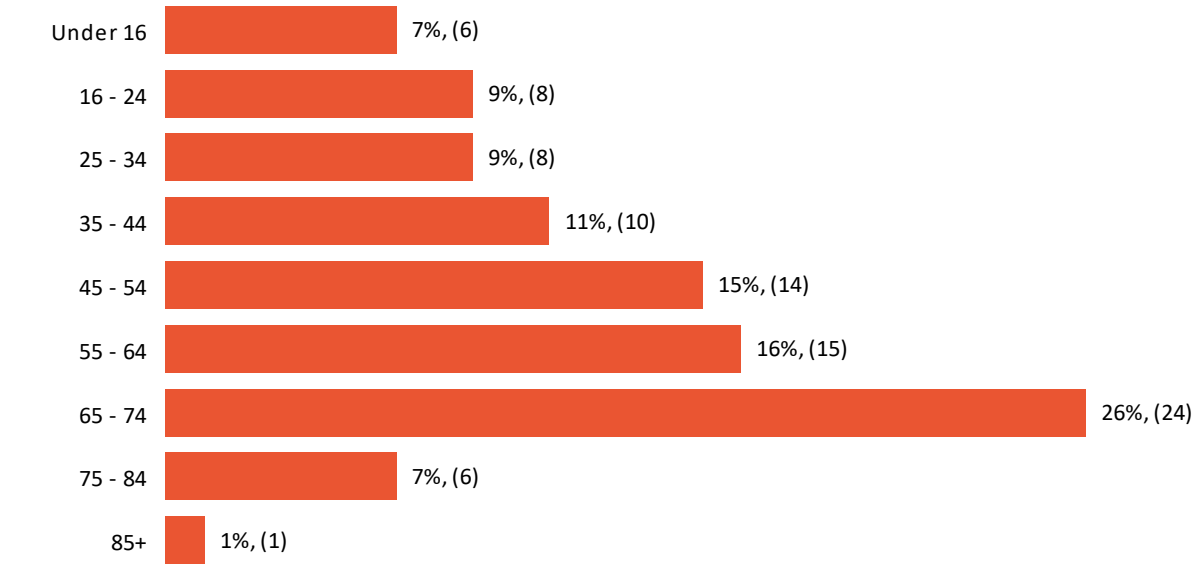
Of the 70 respondents who reported having Haemophilia A or B, 61% said it was severe, 20% said it was moderate and 19% said it was mild.

Of the 23 respondents who reported having Von Willebrand Disease, 30% said it was type 3, 43% said type 2, 13% said type 1, and 13% said they did not know what type they had.

3.2.3 Age

Q54. Age band (From *What is your year of birth?*)



Based on 92 responses (4 people did not answer the question).

3.2.4 Gender

The majority of respondents were male, 77%, with the remaining 23% saying they were female.

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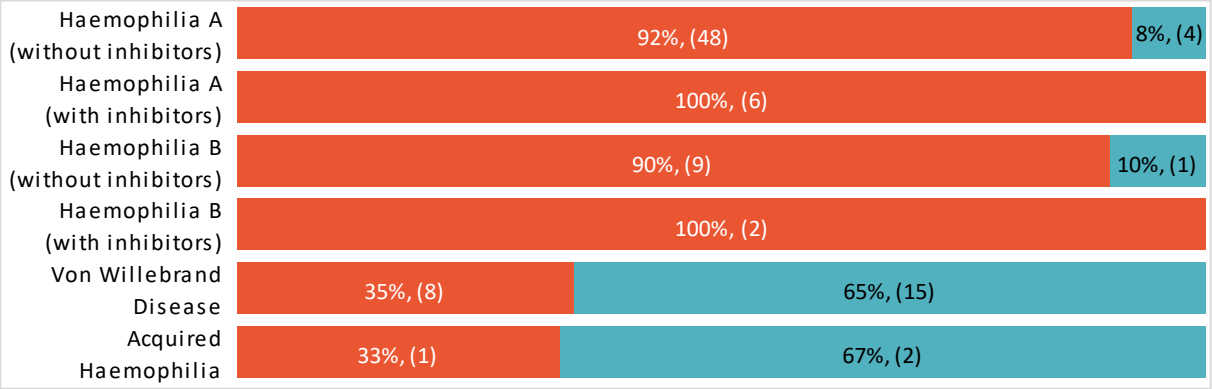
The chart below illustrates how many males and females had each type of bleeding disorder.



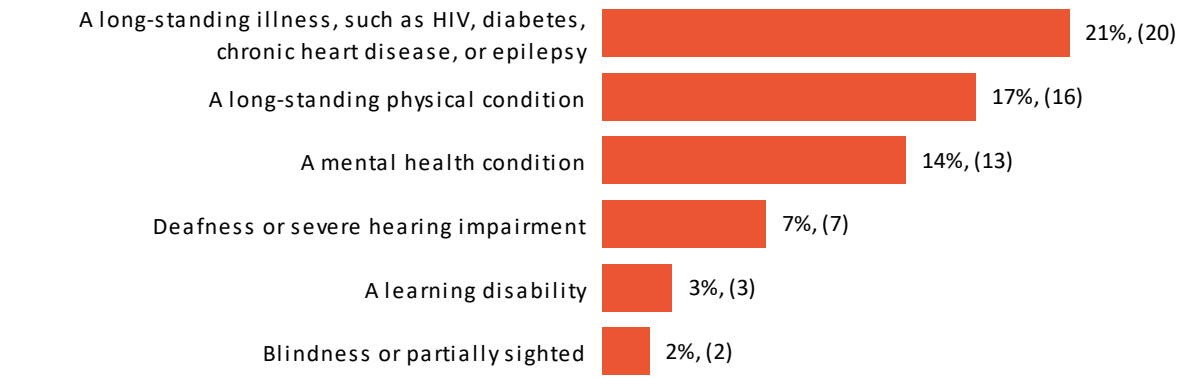
3.2.5 Sexual orientation

89% of respondents were heterosexual, 6% were non-heterosexual and 4% did not wish to say (2 people did not answer the question).

3.2.6 Co-morbidities

Just over a fifth of respondents (21%) reported having a long-standing illness (such as HIV, diabetes, chronic heart disease, or epilepsy) in addition to their blood disorder. The chart below illustrates the full range of additional long-standing conditions.

Q57. In addition to your bleeding disorder, do you have any of the following long-standing conditions?



Tick all that apply question.

3.2.7 Ethnicity

97% of respondents identified as white, 2% said mixed background and 1% were Asian.

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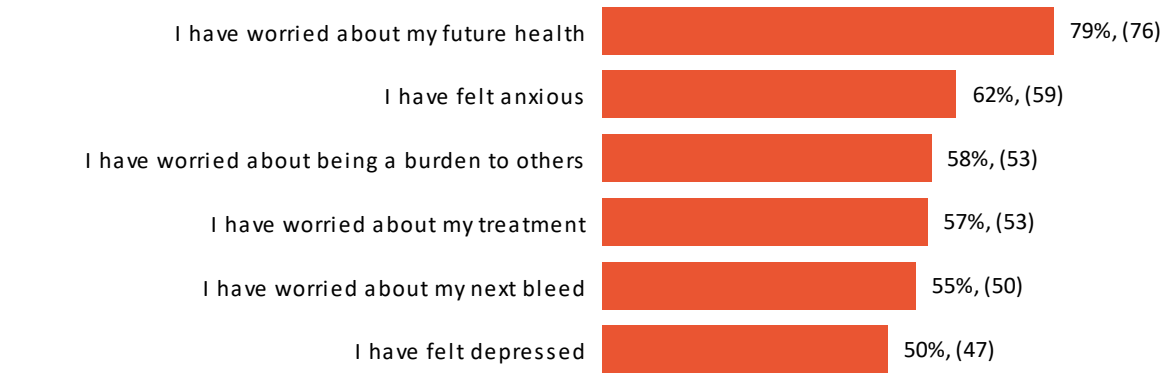
3.3 Quality of life and living with a bleeding disorder

3.3.1 Emotional wellbeing

Respondents were asked to choose extent they had experienced the following concerns, as a result of their bleeding disorder, in the last year. **The response scale was not at all, a little, a lot or not applicable.**

- I have felt anxious
- I have felt depressed
- I have worried about being a burden to others
- I have worried about my treatment
- I have worried about my future health
- I have worried about my next bleed

Q05a – Q05f. Please select the box which best describes to what extent these things have affected you, as a result of your bleeding disorder, in the last year



Those responding, "A little" / "A lot" from a response range of "Not at all" / "A little" / "A lot". Those responding "Not applicable" excluded from percentage calculations.

The biggest worry respondents reported in the last year was around their future health. 79% (76 out of 96 respondents) said that they felt worried, this includes nearly a third (31 out of 96 respondents) who said they worried about this a lot.

Over half of respondents worried a little or a lot about their next bleed (55%, 50 out of 91 respondents).

Respondents reported feeling more anxious than depressed in the last year. Relatively high percentages reported symptoms of anxiety and depression related to their condition, with 62% (59 out of 95 respondents) saying that they felt anxious a little or a lot, while 50% (47 out of 94 respondents) felt depressed a little or a lot.

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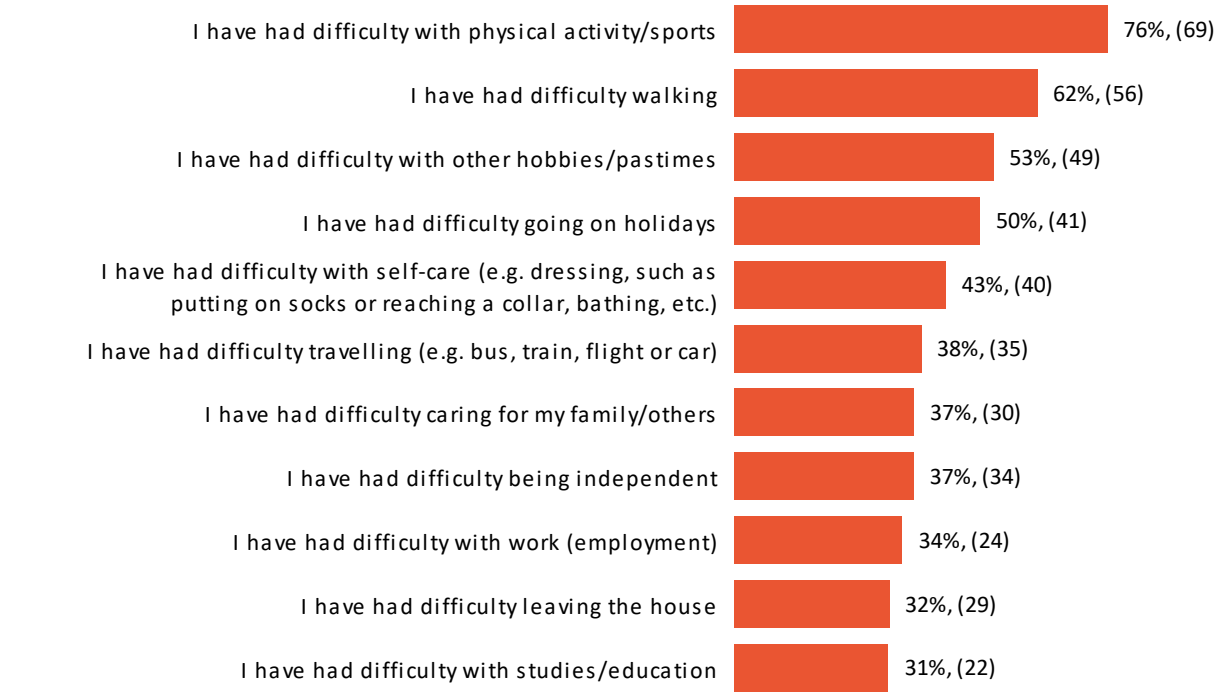
3.3.2 Physical wellbeing

Respondents were asked to choose the extent they had difficulties with the following physical behaviours as a result of their bleeding disorder, in the last year. **The response scale was not at all, a little, a lot or not applicable.**

- I have had difficulty walking
- I have had difficulty with self-care (e.g. dressing, such as putting on socks or reaching a collar, bathing, etc.)
- I have had difficulty being independent
- I have had difficulty caring for my family/others
- I have had difficulty with physical activity/sports
- I have had difficulty with other hobbies/pastimes
- I have had difficulty travelling (e.g. bus, train, flight or car)
- I have had difficulty leaving the house
- I have had difficulty with work (employment)
- I have had difficulty with studies/education
- I have had difficulty going on holidays

Q06a – Q06k. Please select the box which best describes to what extent these things have affected you, as a result of your bleeding disorder, in the last year



Those responding, "A little" / "A lot" from a response range of "Not at all" / "A little" / "A lot". Those responding "Not applicable" excluded from percentage calculations.

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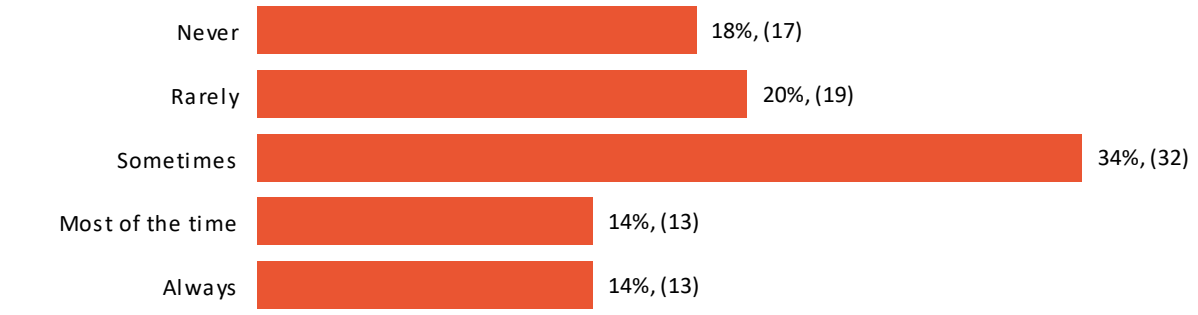
Respondents reported the most effect on their ability to undertake physical activity/sports. Overall, 76% (69 out of 91 respondents) said that they have had some difficulty, this includes a third (30 out of 91 respondents) saying they had a lot of difficulty.

Following on from physical activity, 62% (56 out of 91 respondents) said that they had some difficulty walking, with just over a quarter (24 out of 91 respondents) reporting a lot of difficulty.

3.3.3 Pain

Over a quarter of respondents (26 out of 94) said that they experience pain as a result of their bleeding disorder always/most of the time. 34% (32 out of 94 respondents) reported sometimes experiencing pain, with 38% (36 out of 94 respondents) saying rarely/never.

Q07. In the last year how often did you experience pain as a result of your bleeding disorder?



Based on 94 responses.

3.3.4 Spontaneous bleeds

63% of respondents (59 out of 93) reported having a spontaneous bleed in the last year which they had self-managed, 37% (34 out of 93 of respondents) reported having a spontaneous bleed in the last year which required intervention.

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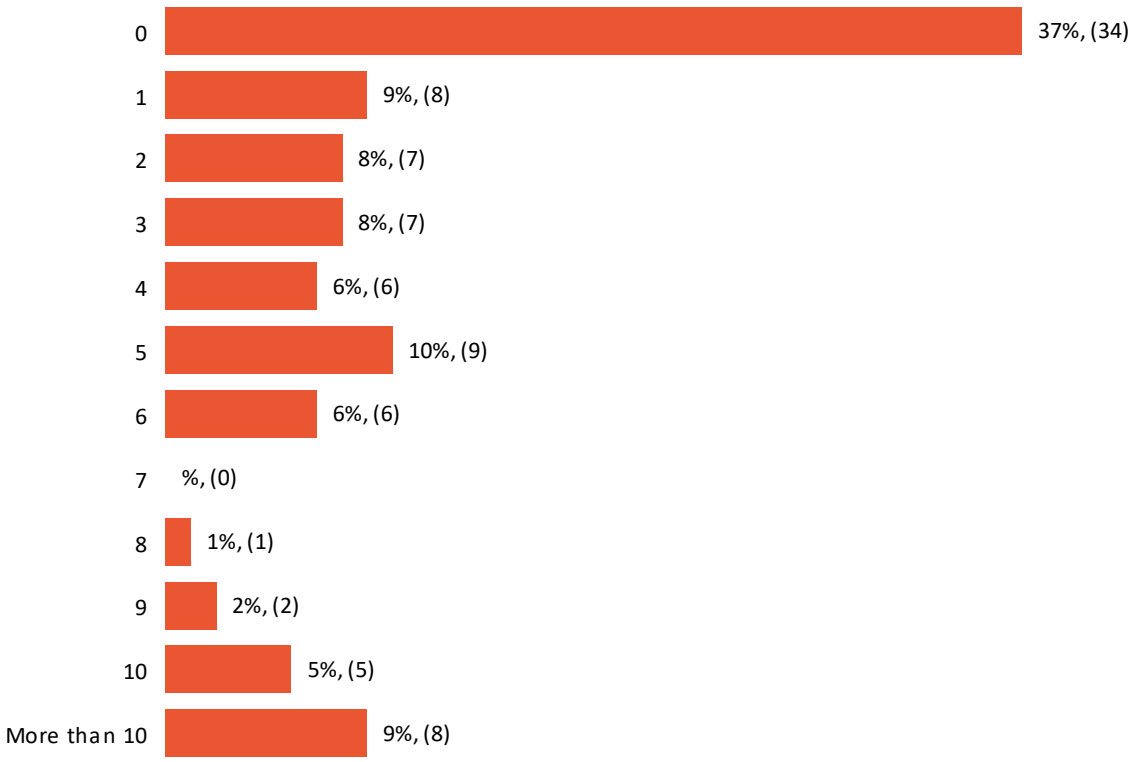
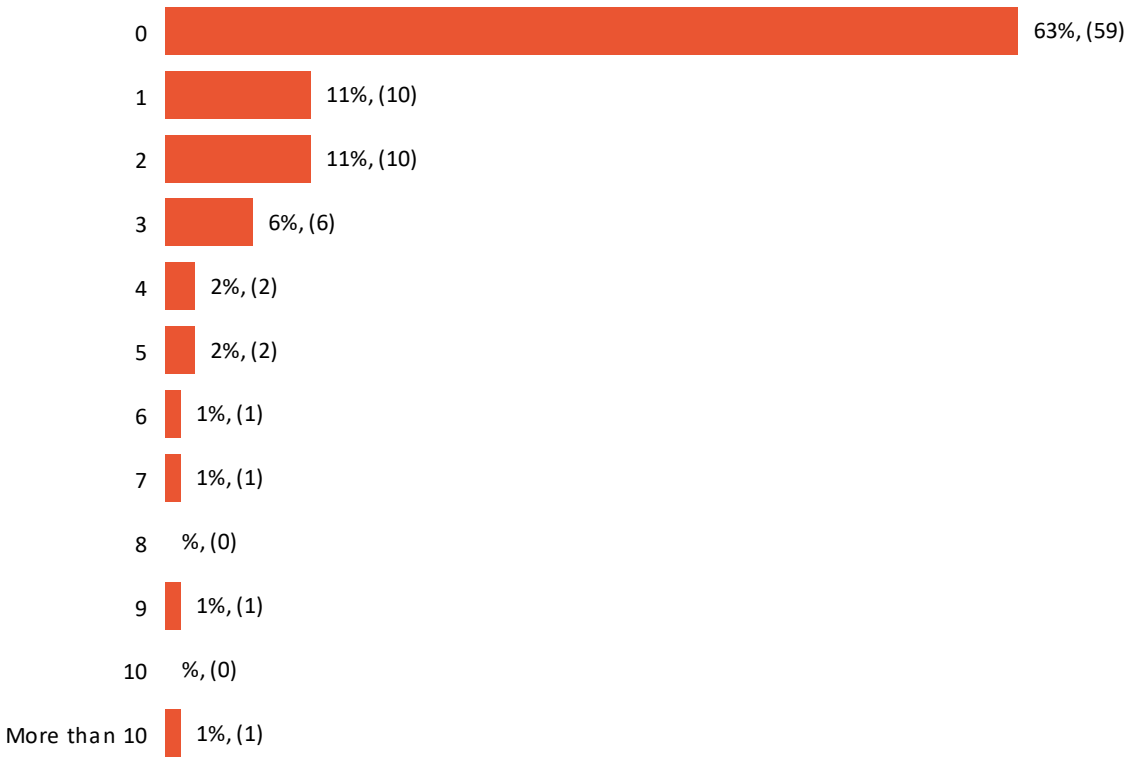
Q08. Approximately how many times in the last year did you experience spontaneous bleeds which you have self-managed?



Based on 93 responses.

Q09. Approximately how many times in the last year did you experience spontaneous bleeds that have required an intervention?



Based on 93 responses.

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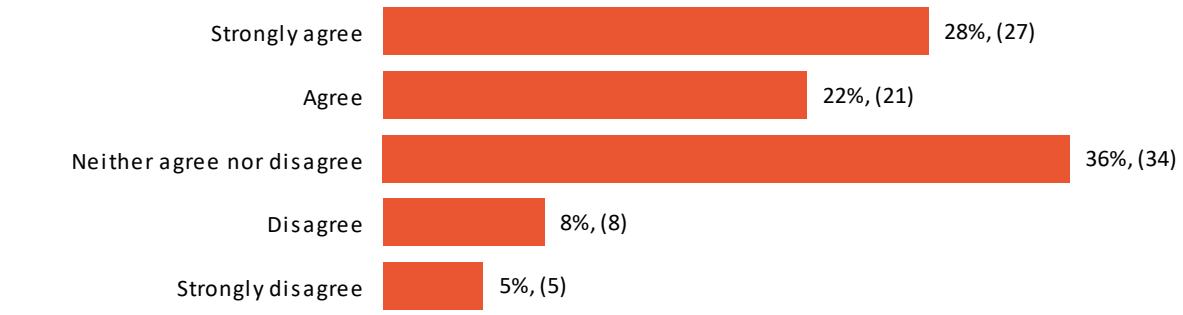
3.3.5 Living with a bleeding disorder

51% of respondents (48 out of 95) strongly agree/agree that they plan their treatment to allow them to do the activities they want to do, 14% (13 out of 95 respondents) strongly disagree/disagree, and 36% (34 out of 95 respondents) gave a neutral response.

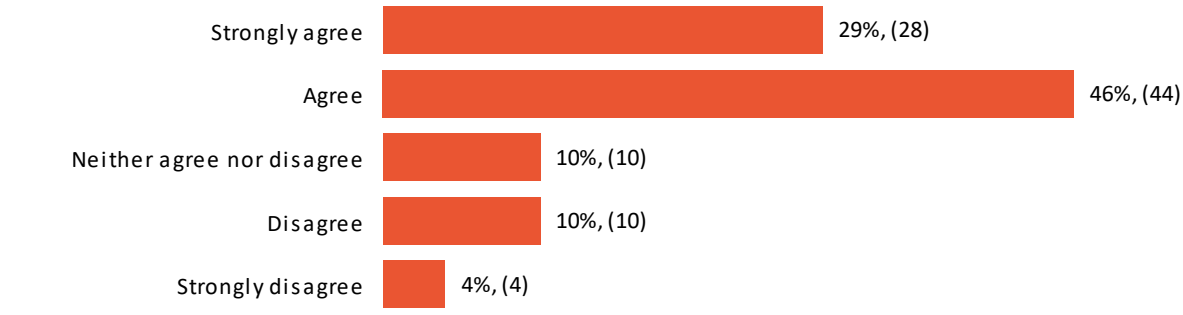
Q10a. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? I plan my treatment to allow me to carry out the activities I want to do.



Based on 95 responses.

Three quarters of respondents (72 out of 96) strongly agree/agree that they avoid certain activities as they think they are too risky, 15% (14 out of 96 respondents) strongly disagree/disagree and 10% (10 out of 96 respondents) gave a neutral response.

Q10b. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? I avoid certain activities as I think they are too risky.



Based on 96 responses.

54% of respondents (51 out of 94) strongly agree/agree that their healthcare team supports them to carry out all the activities they want to do, 13% (12 out of 94 respondents) strongly disagree/disagree and 33% (31 out of 94 respondents) gave a neutral response.

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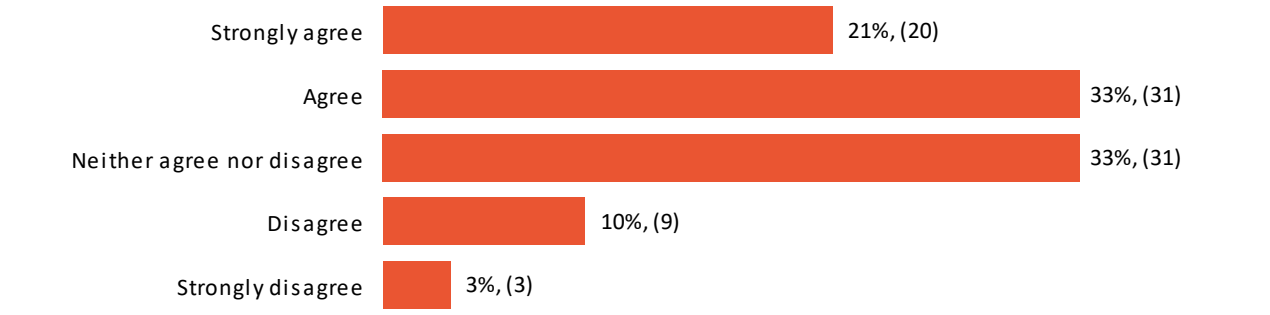
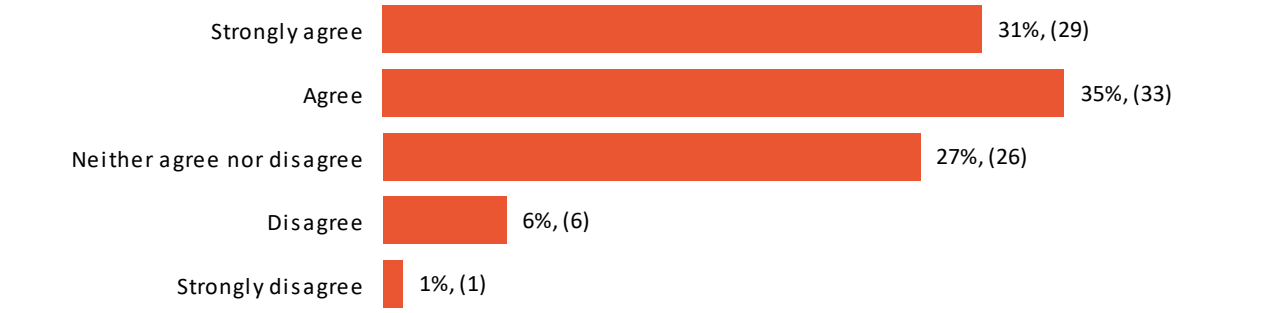
Q10c. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? My healthcare team support me to carry out all the activities I want to do.



Based on 94 responses.

65% of respondents (62 out of 95) strongly agree/agree that their family supports them to carry out all the activities they want to do, 7% (7 out of 95 respondents) strongly disagree/disagree and 27% (26 out of 95 respondents) gave a neutral response.

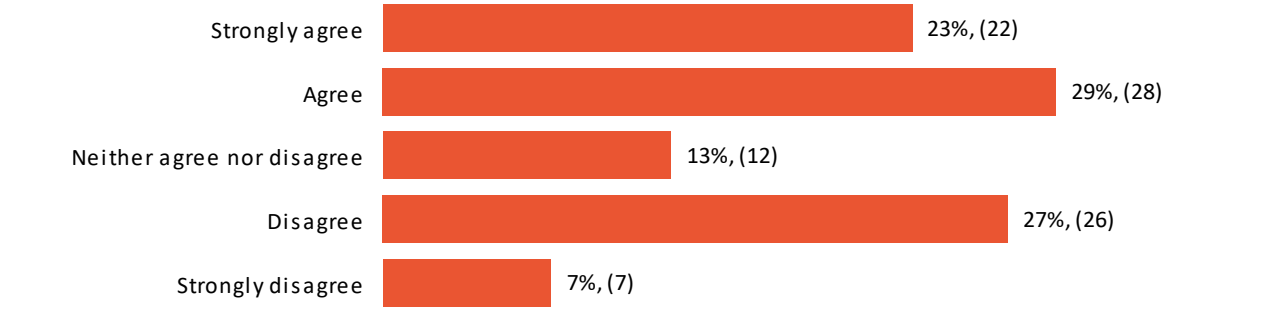
Q10d. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? My family support me to carry out all the activities I want to do.



Based on 95 responses.

53% of respondents (50 out of 95) strongly agree/agree that they are able to carry out **all** of the activities they want to do, 35% (33 out of 95 respondents) strongly disagree/disagree and 13% (12 out of 95 respondents) gave a neutral response.

Q10e. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? I feel I am able to carry out all the activities I want to do.



Based on 95 responses.

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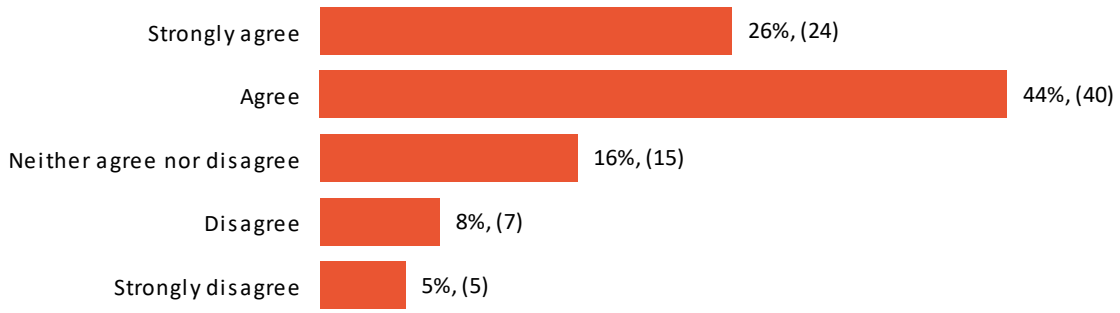
70% of respondents (64 out of 91) strongly agree/agree that they are able to carry out **some** of the activities they want to do, 13% (12 out of 91 respondents) strongly disagree/disagree and 16% (15 out of 91 respondents) gave a neutral response.

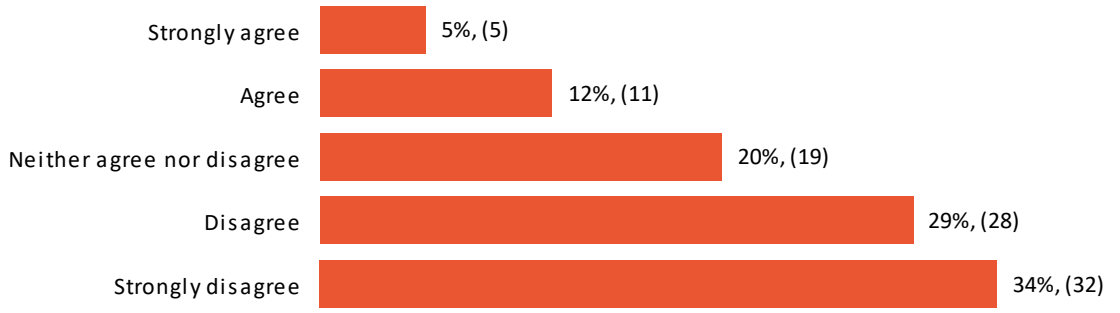
Q10f. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? I feel I am able to carry out some of the activities I want to do.



Based on 91 responses.

17% of respondents (16 out of 95) strongly agree/agree that they are able to carry out **none** the activities they want to do, 63% (60 out of 95 respondents) strongly disagree/disagree and 20% (19 out of 95 respondents) gave a neutral response.

Q10g. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? I feel I am not able to carry out any of the activities I want to do.



Based on 95 responses.

13% of respondents (12 out of 95) strongly agree/agree that their healthcare team has advised them that they cannot do an activity they would like to do, 65% (62 out of 95 respondents) strongly disagree/disagree and 22% (21 out of 95 respondents) gave a neutral response.

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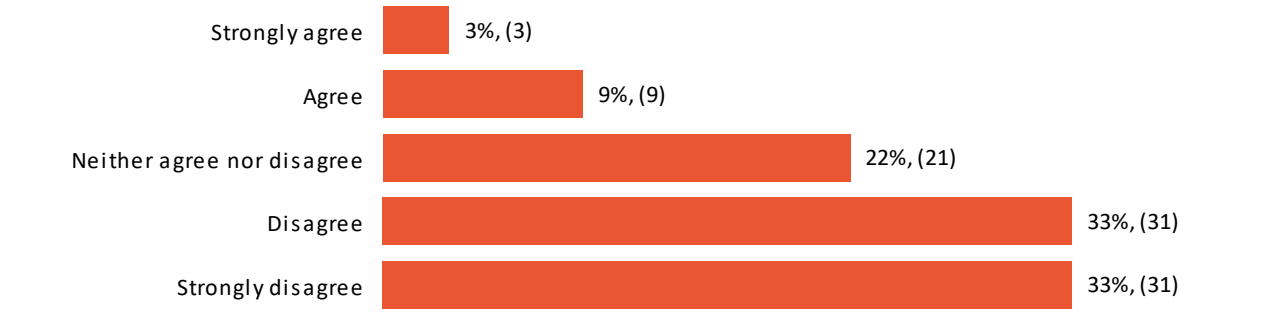
Q10h. Thinking about how your bleeding disorder affects your life, how much do you agree or disagree with the following statements? My healthcare team has advised me I cannot do an activity I would like to do.



Based on 95 responses.

Just over a third of respondents (36 out of 95) said that the healthcare professionals they see at their main place of treatment definitely asks them questions about how their bleeding disorder affects other areas of their life. 40% (38 out of 95 respondents) said that this happens to an extent, and 22% (21 out of 95 respondents) reported no.

Q11. Do the healthcare professionals you see at your main place of treatment ask you questions about how your bleeding disorder affects other areas of your life?

Based on 95 responses. Those responding, "Don't know/not sure" (1) excluded from percentage calculations.

3.3.6 Overall quality of life

Respondents were asked to rate their quality of life whilst living with a bleeding disorder in the last year.

The average score was 6.64.

A quarter of respondents (24 out of 95) gave a low ranging score of 0-4, 24% (23 out of 95 respondents) gave an intermediate score of 5-7 and 51% (48 out of 95 respondents) gave a high score of 8-10. The full range of responses is shown in the following chart:

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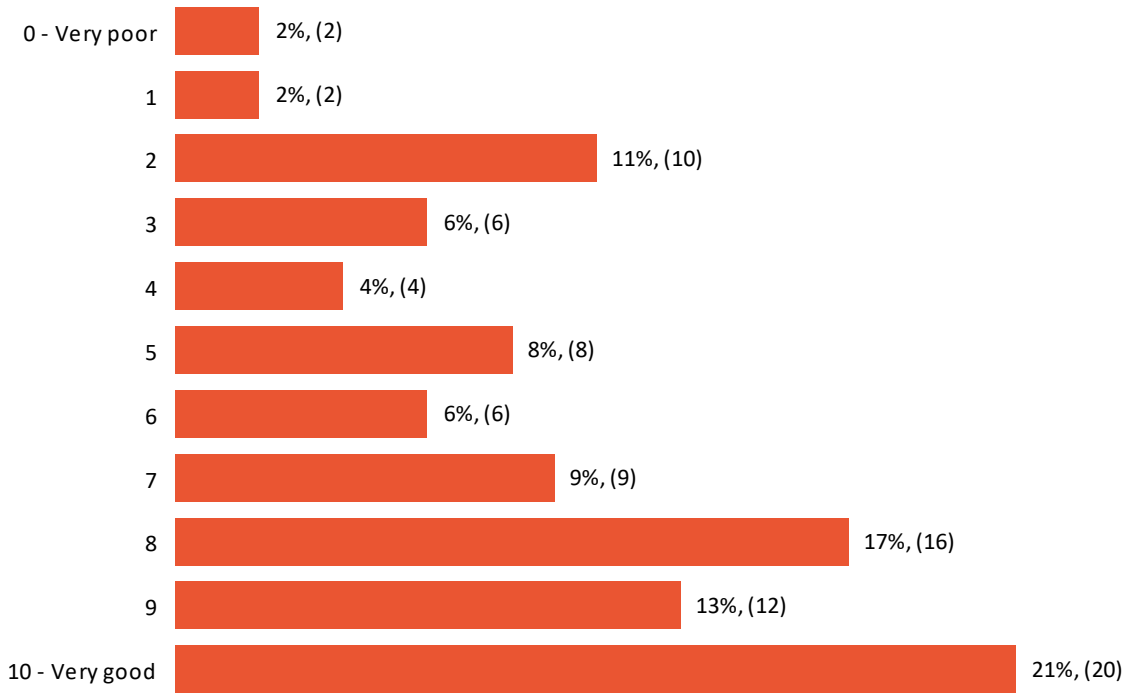
Q12. Overall, in the last year, how would you rate your quality of life whilst living with a bleeding disorder?



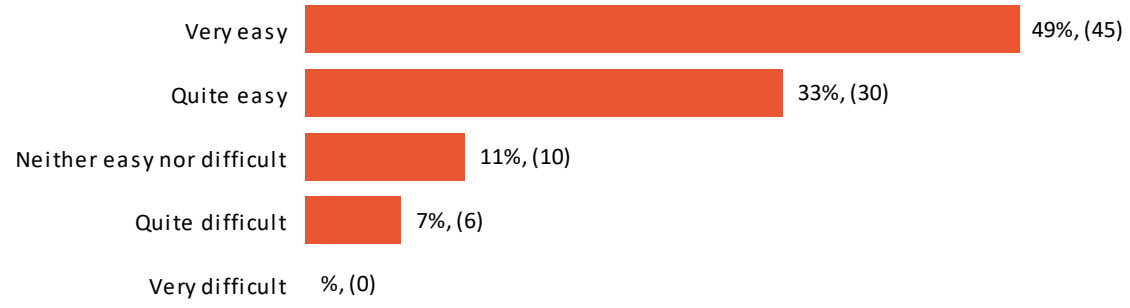
Based on 95 responses. Please note the timeframe of the fieldwork coincided with the COVID-19 pandemic.

3.4 Access to care

3.4.1 Contacting the treatment centre

The majority of respondents (75 out of 91)) said that in the last year it was very/quite easy to contact someone at their treatment centre, 7% (6 out of 91 respondents) said it was quite difficult, 11% (10 out of 91 respondents) gave a neutral answer and no-one reported it being very difficult. Five people had not tried to make contact with their centre and therefore were not included in the analysis.

Q15. In the last year, how easy or difficult was it for you to contact someone at your treatment centre?



Based on 91 responses. Those responding, "I had not tried to contact them" (5) excluded from percentage calculations. Please note the timeframe of the fieldwork coincided with the COVID-19 pandemic.

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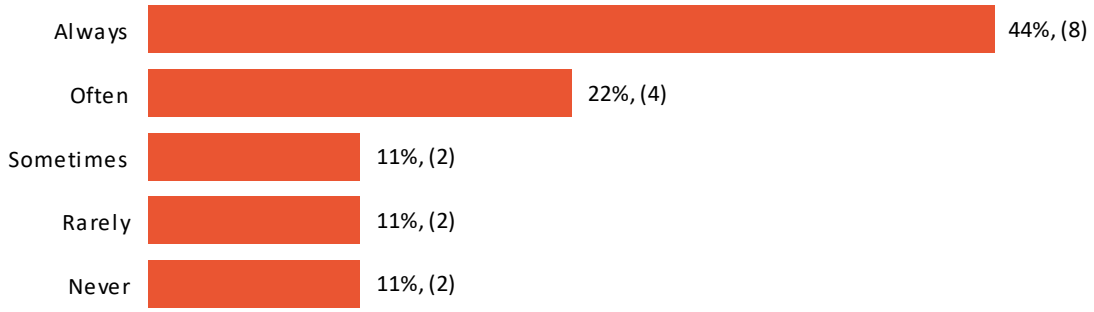
3.4.2 Emergency care

22% of respondents (21 out of 96) had to attend A&E for an emergency visit relating to their bleeding disorder in the last year.

Only the 21 respondents who attended A&E in the last year answered the questions in this section of the survey.

Two thirds of respondents (12 out of 18) reported that, when they attended A&E, the healthcare team they saw always/often asked about their bleeding disorder. 11% (2 out of 18 respondents) said this sometimes happened, and 22% (4 out of 18 respondents) said it rarely/never happened. Three people answered don't know/can't remember and were therefore excluded from the analysis.

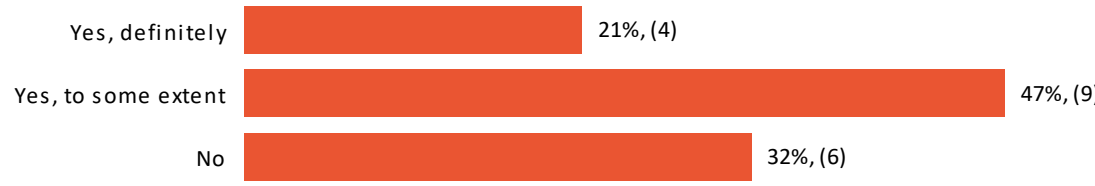
Q18. When you attended A&E, did the healthcare team you saw ask about your bleeding disorder?



Based on 18 responses. Those responding, "Don't know/can't remember" (3) excluded from percentage calculations.

21% of respondents (4 out of 19) felt that the healthcare team they saw in A&E definitely understood how to treat/care for their bleeding disorder. 47% (9 out of 19 respondents) felt they understood to some extent and 32% (6 out of 19 respondents) didn't think the healthcare team knew how to treat/care for their bleeding disorder. Two people answered don't know/can't remember and were therefore excluded from the analysis.

Q19. Do you feel that the healthcare team you saw in A&E understood how to treat/care for your bleeding disorder?



Based on 19 responses. Those responding, "Don't know/can't remember" (2) excluded from percentage calculations.

Respondents were asked what outcomes they had experienced when attending A&E in the last year, this question was tick all that apply, so they could give more than one answer. 52% (11 out of 21 respondents) said they were given treatment in A&E and 52% (11 out of 21 respondents) said they had been sent elsewhere for treatment (e.g. Haematology Unit, Haemophilia Centre). 1 person said they had been discharged without treatment. One person answered don't know/can't remember.

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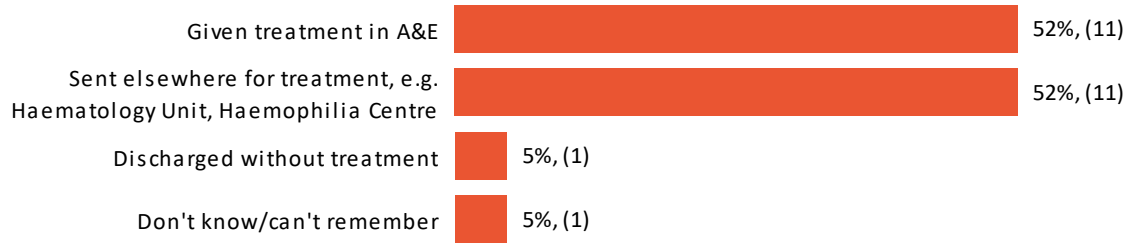
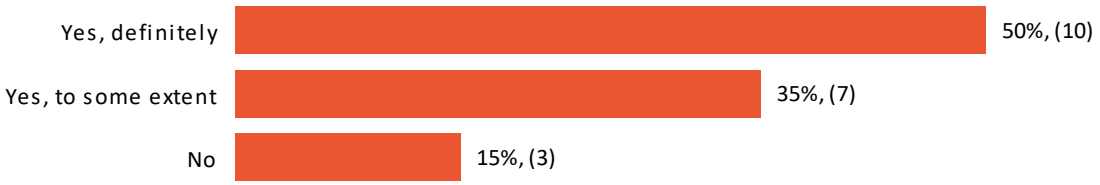
Q20. What outcomes did you experience when attending A&E?



Tick all that apply question.

50% of respondents (10 out of 20) felt that when they attended A&E, they definitely got the treatment/care they needed. 35% (7 out of 20 respondents) felt this happened to some extent and 15% (3 out of 20 respondents) didn't think they got the care and treatment they needed. One person answered don't know/can't remember and therefore was excluded from the analysis.

Q21. When you attended A&E, did you feel you got the treatment/care you needed?



Based on 20 responses. Those responding, "Don't know/can't remember" (1) excluded from percentage calculations.

3.5 Involvement in treatment and care

3.5.1 Treatment language

The 73 respondents with Haemophilia were asked if they understood the following treatment terms or knew what they stood for:

- SHL prophylaxis
- SHL on demand
- EHL prophylaxis
- EHL on demand
- Non-factor replacement therapy

In all cases the majority of respondents did not know what these treatments were. The highest level of understanding was for SHL on demand where 45% of respondents (32 out of 71 respondents) **did** understand the term. The lowest level of understanding was for EHL on demand where 62% (44 out of 71 respondents) **did not** understand the term.

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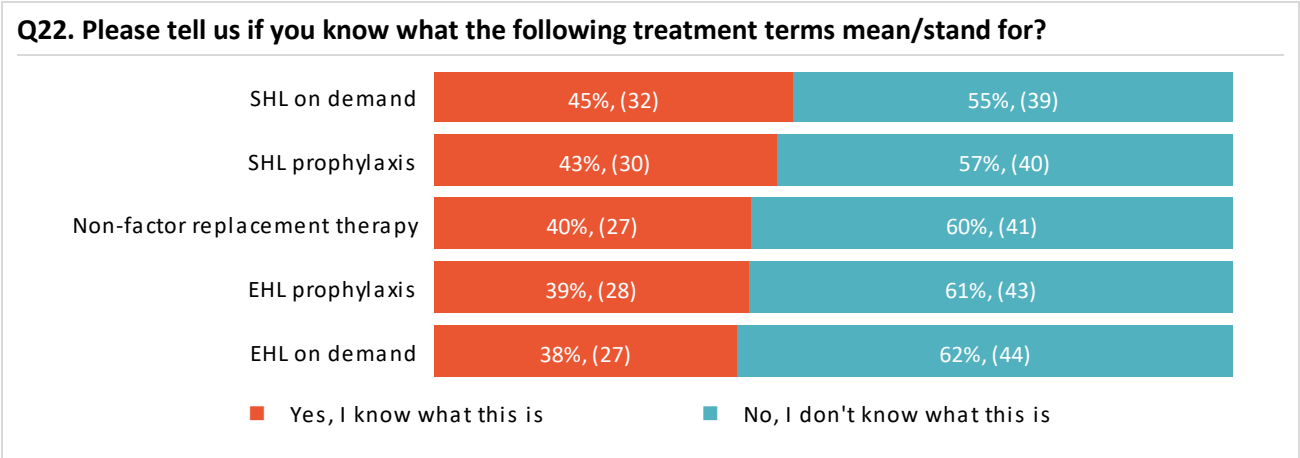

3.5.2 Treatment for Haemophilia

Respondents with Haemophilia were asked what their main treatment plan had been in the last year. 30% (22 out of 73 respondents) said that they had been on SHL prophylaxis, 15% (11 out of 73 respondents) said EHL prophylaxis, 14% (10 out of 73 respondents) said SHL on demand, 5% (4 out of 73 respondents) said non-factor replacement therapy, and 3% (2 out of 73 respondents) said EHL on demand. 22% (16 out of 73 respondents) answered other and 11% (8 out of 73 respondents) said that they didn't know.

All of the respondents who answered other (16 people) and 3 who said don't know, used the free text box to describe what treatment they were on. Many of the descriptions given were generic terms or brand names that could have been classified within the available answer options.

3.5.3 Tailoring treatment

Respondents were asked if they have had a conversation about tailoring their treatment to their desired lifestyle. 39 people out 96 of said they had not had a conversation but that it had not been necessary and 4 out of 96 said they don't know/not sure, therefore both these groups have been excluded from the analysis. 77% (41 out of 53 people) answered yes, 17% (9 out of 53 respondents) said they have not had this conversation but would like to, and 6% (3 out of 53 respondents) said they asked about tailoring their treatment but the person they spoke with did not want to engage in the conversation.

The next three questions were only asked to the 41 respondents who reported having a conversation about tailoring their treatment, not all 41 answered all the questions.

50% (20 out of 40) said the conversation was initiated by their healthcare team. 35% (14 out of 40 respondents) said they, the patient, initiated it, 5% (2 out of 40 respondents) said a parent/guardian, 5% (2 out of 40 respondents) said other (and reported it was a joint initiation), and 5% (2 out of 40 respondents) said they don't know/can't remember.

Respondents were asked what outcomes they had experienced following their conversation about tailoring treatment, this question was tick all that apply, so they could give more than one answer.

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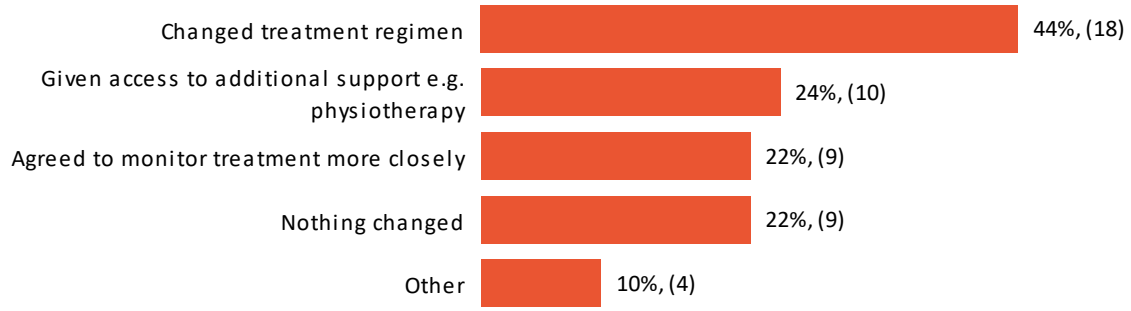
Q26. What was the outcome of the conversation?



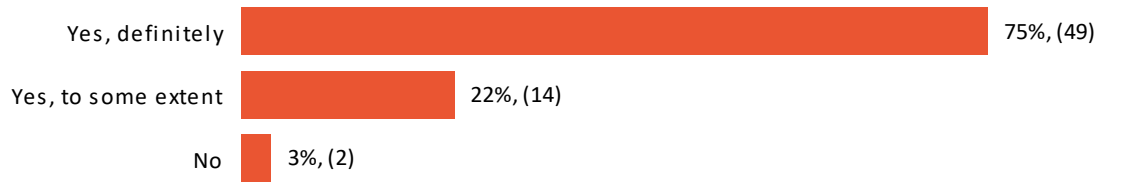
Tick all that apply question. Based on 41 responses.

Excluding those who said don't know or not sure (4 people), 100% (37 people) of those who had a conversation about tailoring treatment were satisfied with the outcome.

3.5.4 Treatment review

70% of respondents (65 out of 93) said that they had regular reviews of their treatment plan in the last year. Of these patients 75% (49 out of 65 respondents) said that in their last review they definitely had enough time to discuss their needs and treatment.

Q29. In your last review, did you feel you had enough time to discuss your needs and treatment?

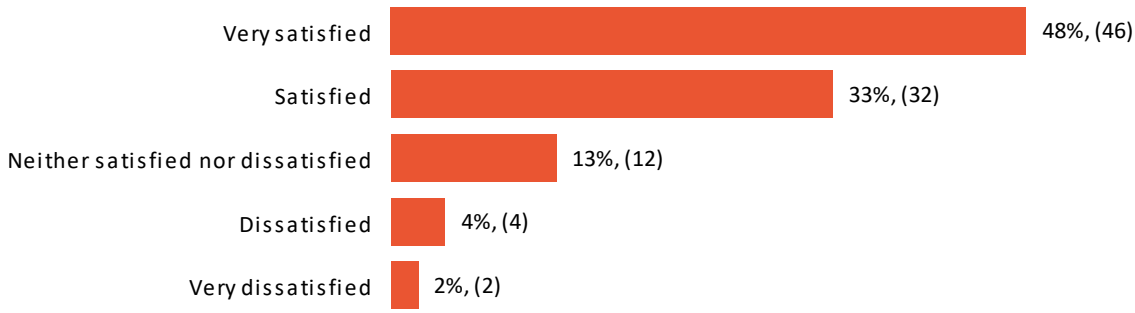


Based on 65 responses.

3.5.5 Satisfaction with treatment

81% of respondents (78 out of 96 respondents) are very satisfied/satisfied with how their current treatment regime is working, 6% (6 out of 96 respondents) are very dissatisfied/dissatisfied and 13% (12 out of 96 respondents) gave a neutral response.

Q30. How satisfied are you with how your current treatment regimen is working?



Based on 96 responses.

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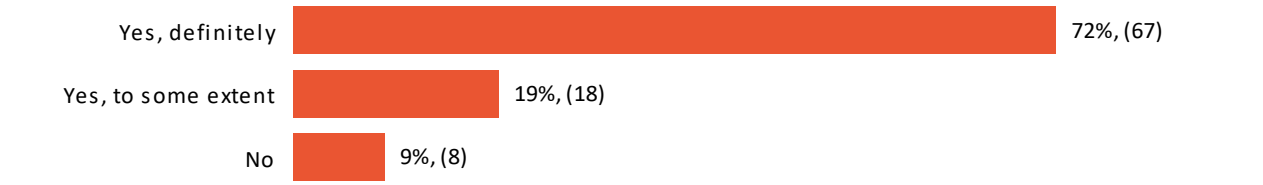
3.5.6 Raising concerns with treatment

72% of respondents (67 out of 93) said that they would definitely feel comfortable raising any concerns they might have about their treatment and care. 19% (18 out of 93 respondents) said they would be to a certain extent, and 9% (8 out of 93 respondents) said they would not feel comfortable. Those responding, don't know/not sure (1) and not applicable (1) have been excluded from the analysis.

Q31. Do you feel comfortable raising any concerns you may have with your treatment and care?



Based on 93 responses. Those responding, "Don't know/not sure" (1) and "Not applicable" (1) excluded from percentage calculations.

3.5.7 Treatment centre discussions

Respondents were asked to report if they ever had discussions with the people they see at their treatment centre on the following topics. Those responding, don't know/not sure and not applicable have been excluded from the analysis.

- New treatment developments
- Switching treatment
- Possibility of entering clinical trials
- The use of technology such as apps to help with treatment
- Tailoring the frequency of treatment to unique biological response
- Side effects of treatment
- Tailoring treatment to patient needs
- How treatment works
- Pain management
- Emergency situations
- Patient alert cards

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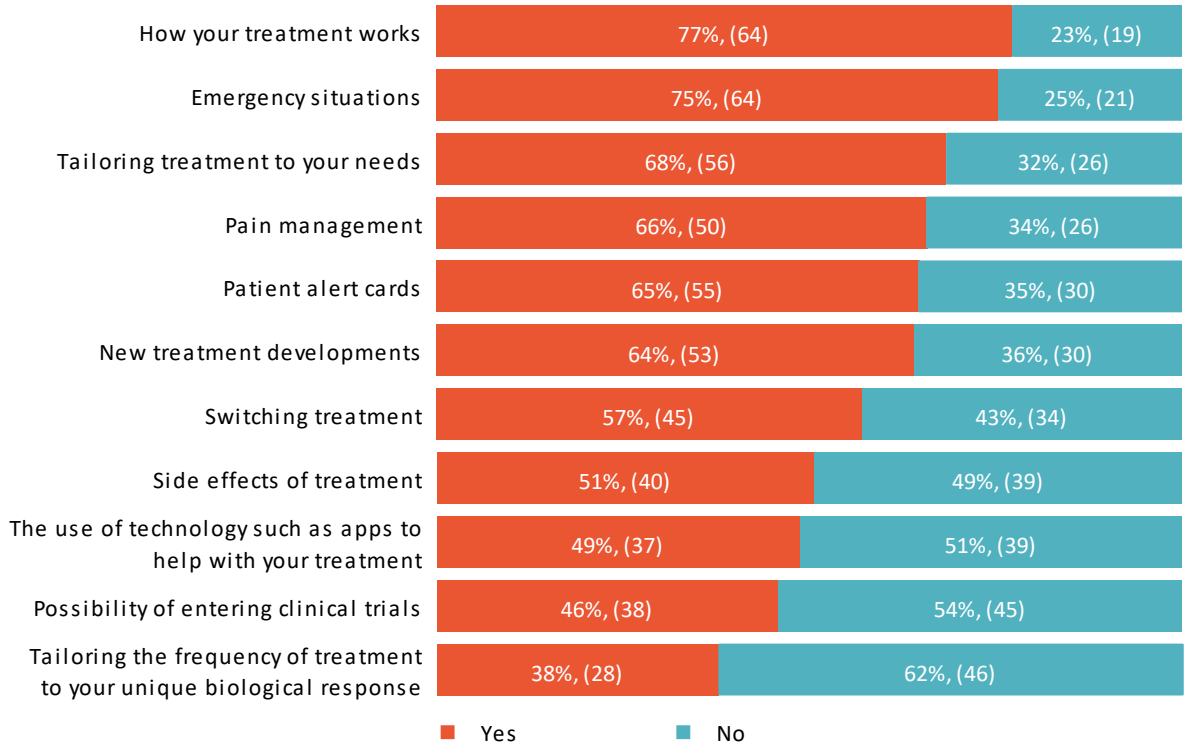
Q32. Do the people you see at the treatment centre ever discuss the following with you?



Those responding, "Don't know/not sure" and "Not applicable" excluded from percentage calculations.

The most discussed topics were how treatment works (77%, 64 out of 83 respondents) and emergency situations (75%, 64 out of 85 respondents). The least disscused topics were tailoring the frequency of treatment to unique biological response (38%, 28 out of 74 respondents), possibility of entering clincal trials (46%, 38 out of 83 respondents), and the use of technology to help with treatment (49%, 37 out of 76 respondents). Furthermore only around half of respondents said they had discussed the side effects of treatment (51%, 40 out of 79 respondents).

3.5.8 Treatment centre feedback

56% of respondents (50 out of 90 respondents) said that they had been asked by their current treatment centre at some point to give their views on the quality of the care and treatment they receive, 44% (40 out of 90 respondents) said they had not been asked.

3.5.9 Joined up care

65% of respondents (60 out of 93) said that the different people treating and caring for them always/most of the time communicate and work well together to give them the best possible care. 28% (26 out of 93 respondents) said that this happens some of the time and 8% (7 out of 93 respondents) said that it never happens.

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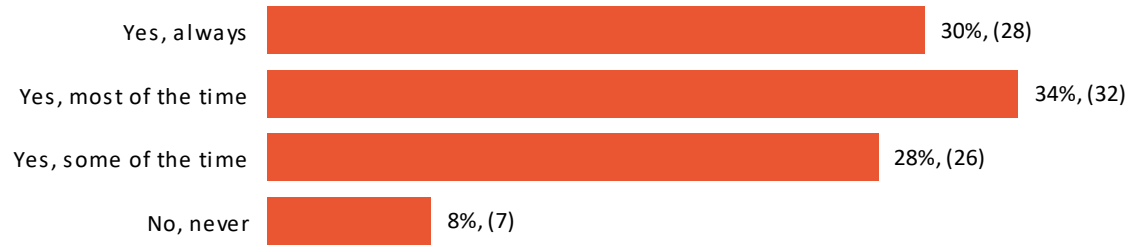
Q34. Do the different people treating and caring for you (such as GP, Haemophilia centre team, social worker, physiotherapist, dentist etc.) communicate and work well together to give you the best possible care?



Based on 93 responses. Those responding, "Don't know/not sure" (3) excluded from percentage calculation.

3.6 Self-management of treatment

78% of respondents (73 out of 94 respondents) reported that they manage their own treatment. This next section excludes the 21 patients who said they do not manage their own treatment.

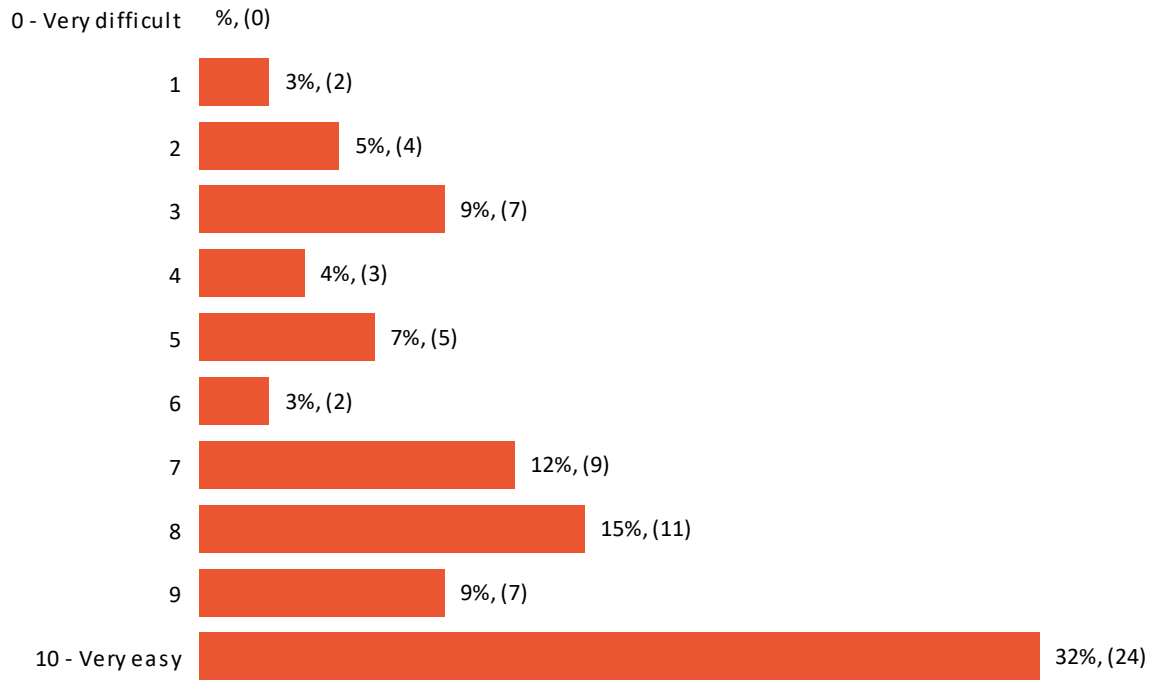
3.6.1 Ease of self-management

Respondents were asked to rate from 0-10, how easy (overall) they find it to manage their own treatment?

The average score was 7.22.

22% (16 out of 74 respondents) gave a low ranging score of 0-4, 22% (16 out of 74 respondents) gave an intermediate score of 5-7 and 57% (42 out of 74 respondents) gave a high score of 8-10. The full range of responses is shown in the chart below:

Q36. Overall, how easy do you find it to manage your own treatment?



Based on 74 responses.

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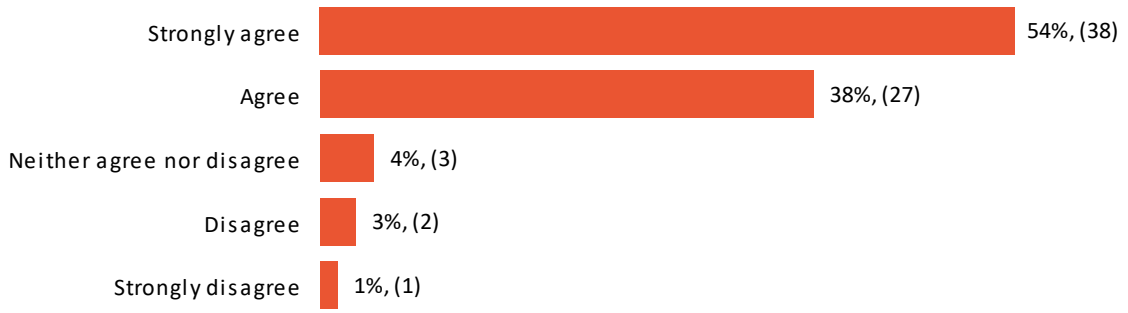
92% of respondents (65 out of 71 respondents) strongly agree/agree that they find managing their own treatment acceptable. 4% (3 out of 71 respondents) strongly disagree/disagree and 4% (3 out of 71 respondents) gave a neutral response.

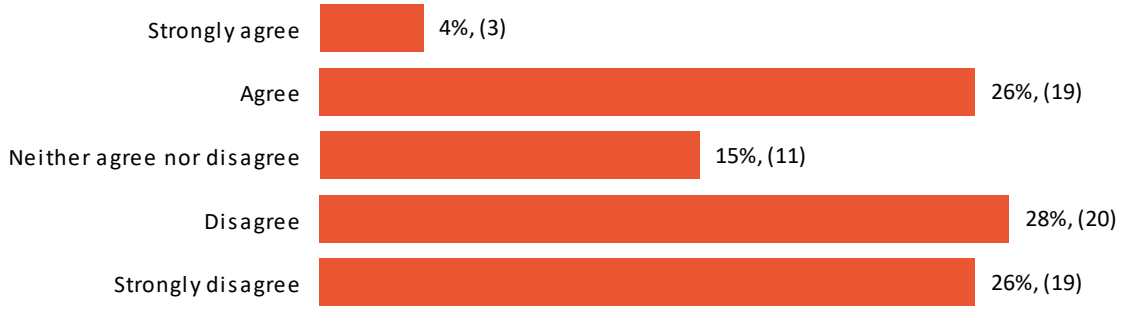
Q37a. I find managing my own treatment... Acceptable



Based on 71 responses.

31% of respondents (22 out of 72 respondents) strongly agree/agree that they find managing their own treatment stressful. 54% (39 out of 72 respondents) strongly disagree/disagree and 15% (11 out of 72 respondents) gave a neutral response.

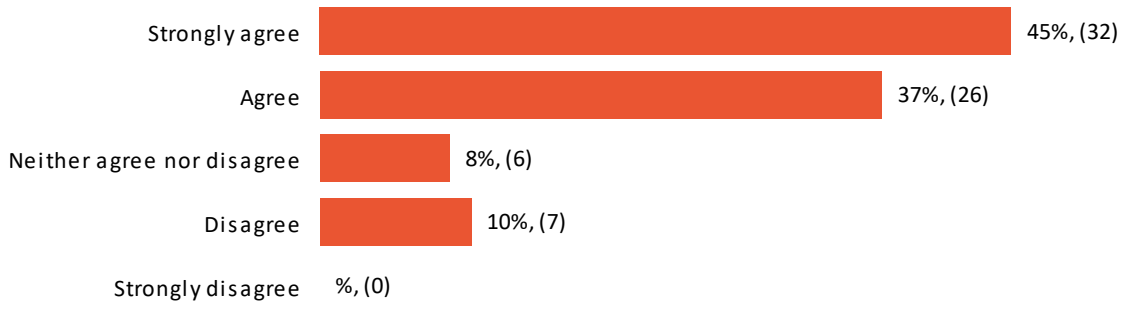
Q37b. I find managing my own treatment... Stressful



Based on 72 responses.

82% of respondents (58 out of 71) strongly agree/agree that they find managing their own treatment convenient. 10% (7 out of 71 respondents) strongly disagree/disagree and 8% (6 out of 71) gave a neutral response.

Q37c. I find managing my own treatment... Convenient



Based on 71 responses.

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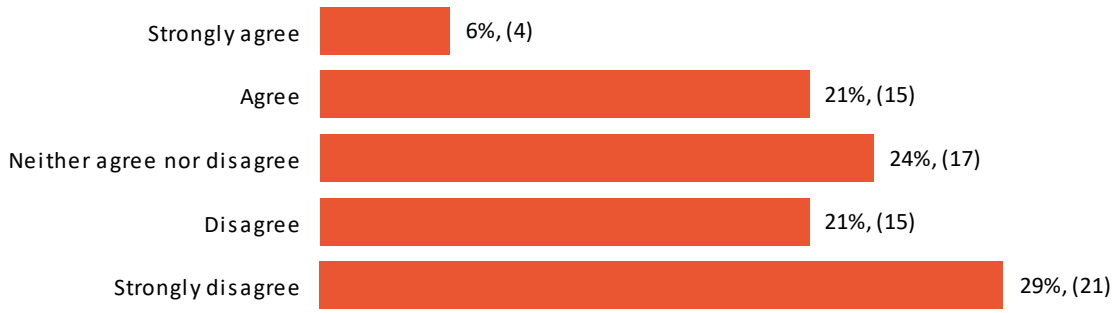
26% of respondents (19 out of 72 respondents) strongly agree/agree that they find managing their own treatment restrictive. 50% (36 out of 72 respondents) strongly disagree/disagree and 24% (17 out of 72 respondents) gave a neutral response.

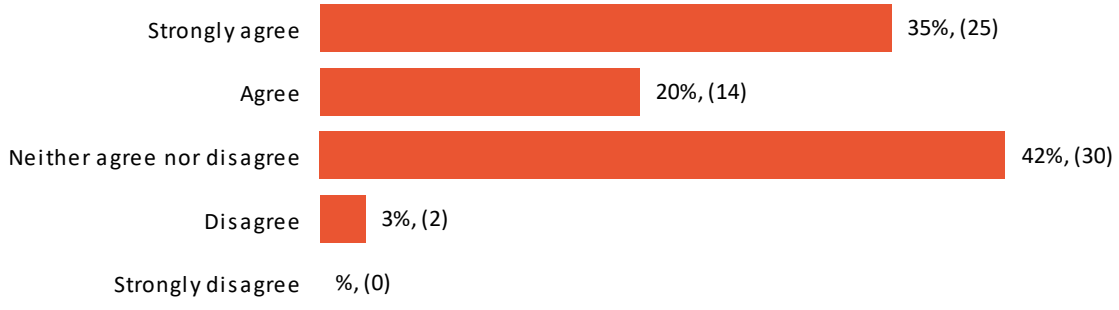
Q37d. I find managing my own treatment... Restrictive



Based on 72 responses.

55% of respondents (39 out of 71) strongly agree/agree that they find managing their own treatment empowering. 3% (2 out of 71 respondents) strongly disagree/disagree and 42% (30 out of 71 respondents) gave a neutral response.

Q37e. I find managing my own treatment... Empowering



Based on 71 responses.

80% of respondents (59 out of 74) say that their healthcare team definitely give them enough information to allow them to manage their condition at home. 16% (12 out of 74 respondents) said that this happens to a certain extent, and 4% (3 out of 74 respondents) said they are not given enough information.

3.7 Additional support

3.7.1 Rating of support from healthcare professionals

Respondents were asked to rate the support they received for their bleeding disorder in the last year from the following professionals. **The scale was excellent, good, average, poor, very poor, not available and do not need.**

- Lead Haemophilia doctor (or lead haematologist)
- Lead Haemophilia nurse (or lead haematology nurse)
- On-call Haemophilia specialist
- Bleeding disorders specialist nurses

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- Clinical specialist physiotherapist
- Specialist psychology staff
- Specialist social workers
- Gynaecologist
- Pharmacist
- Dentist
- Occupational Therapist
- GP (not out of hours service)
- Other

Where people had access to these healthcare professionals, respondents were most positive about the support received from their bleeding disorders specialist nurses in the last year, 94% (72 out of 77 respondents) rated them excellent/good.

The next highest were clinical specialist physiotherapists and lead Haemophilia/haematology nurses, both scoring 91% (59 out of 65, and 78 out of 86 respectively).

Although still overwhelmingly postive the professions who scored lowest were GP (65%, 45 out of 69 respondents), pharmacists (72%, 23 out of 32 respondents) and dentists (79%, 46 out of 58 respondents).

Results for specialist psychology staff, specialist social workers, gynaecologists and occupational therapists have been supressed due to the small number of responses.

The following chart illustrates the number of respondents who reported that support from these health care professionals were not available to them.

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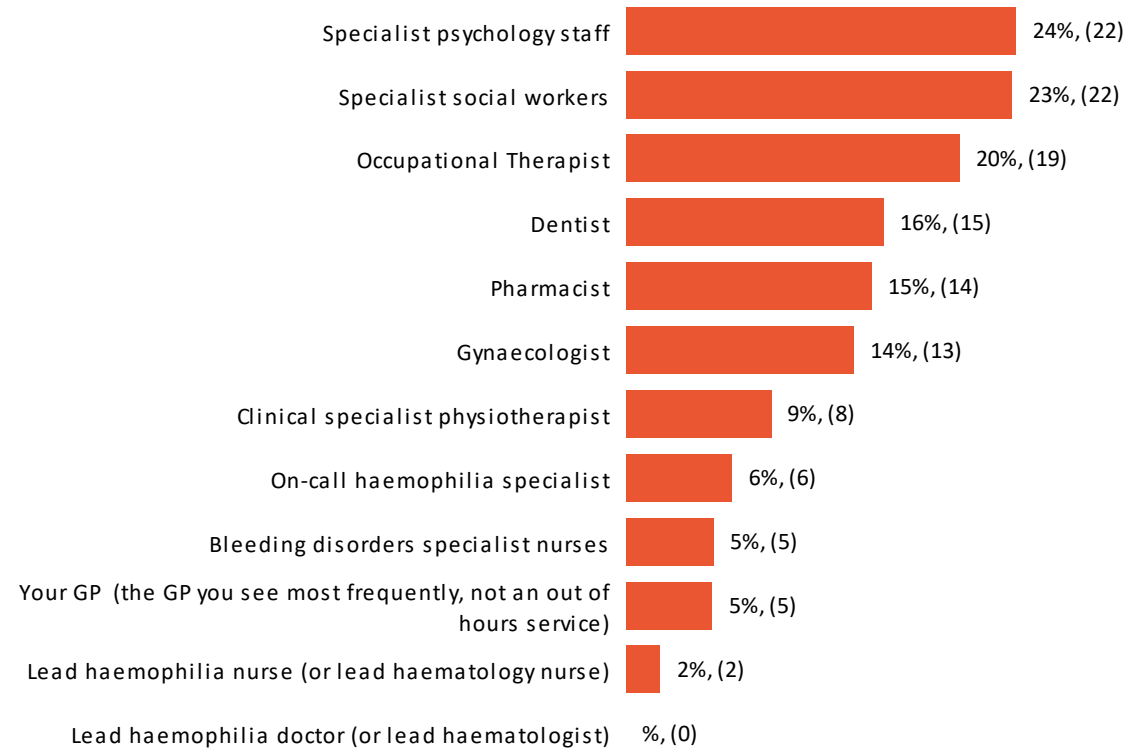
Q39. How would you rate the support you received for Haemophilia or other bleeding disorders from these professionals in the last year? "Not available"

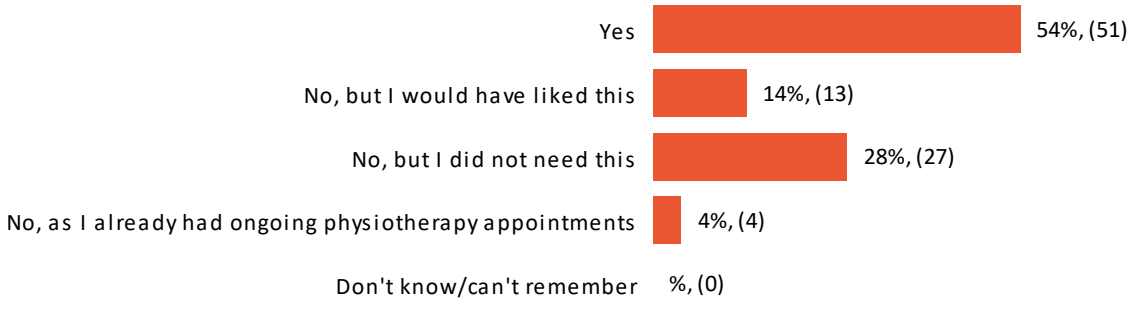


Those responding, "Not available" from a response range of "Excellent", "Good", "Average", "Poor", "Very poor", "Not available" and "Do not need".

3.7.2 Physiotherapy support

Respondents were asked if they had been offered physiotherapy appointments to help with their bleeding disorder in the last year. Just over half of respondents (51 out 95) had been offered a physiotherapy appointment) while 14% (13 out of 95) hadn't been offered an appointment but would have liked to have been. A third of respondents (31 out of 95) indicated that this offering was not necessary, either because they did not need an appointment (27) or because they already had ongoing appointments (4).

Q40. In the last year were you offered physiotherapy appointments to help with your bleeding disorder? All responses



Based on 95 responses.

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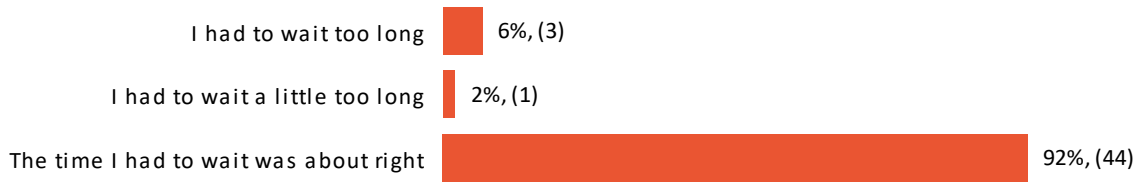
Of the respondents who were offered physiotherapy appointments in the last year 92% of respondents (44 out of 48) said the wait was about right and 8% (4 out of 48 respondents) said the wait was too long/a little too long.

Q41. How did you feel about the amount of time you had to wait for your physiotherapy appointments?

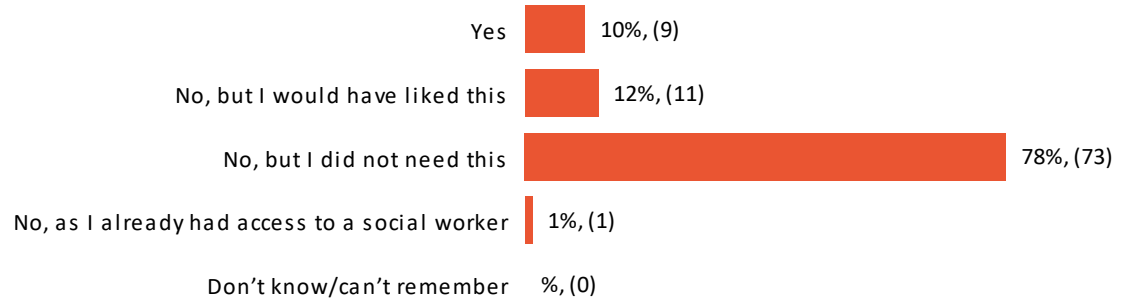


Based on 48 responses. Those responding, "Don't know/not sure" (3) excluded from percentage calculation.

3.7.3 Social work support

Respondents were asked if they had been given access to a social worker to assist with issues related to their bleeding disorder in the last year. The majority of respondents (78%, 74 out of 94 respondents) did not feel this was necessary for them, either because they did not need access (73) or because they already had access (1). 10% of respondents (9 out of 94) were given access while 12% (11 out of 94) were not given access but would have liked to have been.

Q42. In the last year were you given access to a social worker to assist with issues related to your bleeding disorder? All responses



Based on 94 responses.

Of the 9 respondents who were given access to a social worker in the last year, 7 said the wait was about right and 2 said the wait was too long/a little too long.

3.7.4 Psychological support

Respondents were asked if they have been given access to psychological support to assist with issues related to their bleeding disorder in the last year. The majority of respondents (68%, 65 out of 94 respondents) did not feel this was necessary for them, either because they did not need access (64) or because they already had access (1). 5% of respondents (5 out of 94) were given access while 26% (24 out of 94) were not given access but would have liked to have been.

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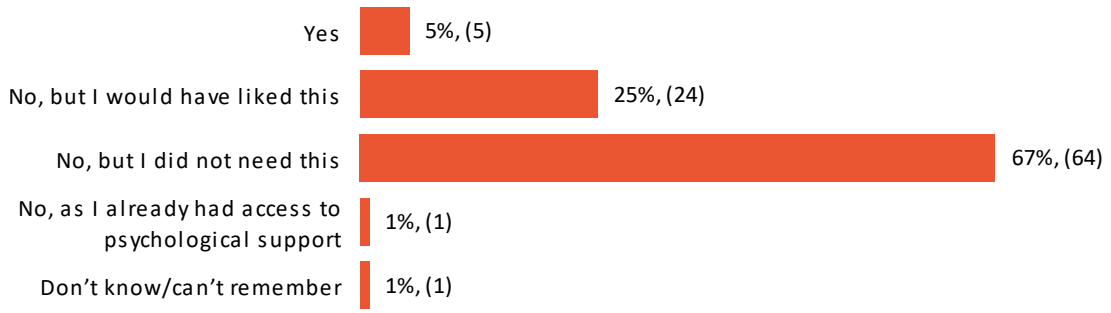
Q44. In the last year were you given access to psychological support to assist with issues related to your bleeding disorder? All responses



Based on 95 responses.

Of the 5 respondents who were given access to psychological support last year, 3 said the wait was about right and 1 said the wait was too long (1 person did not know).

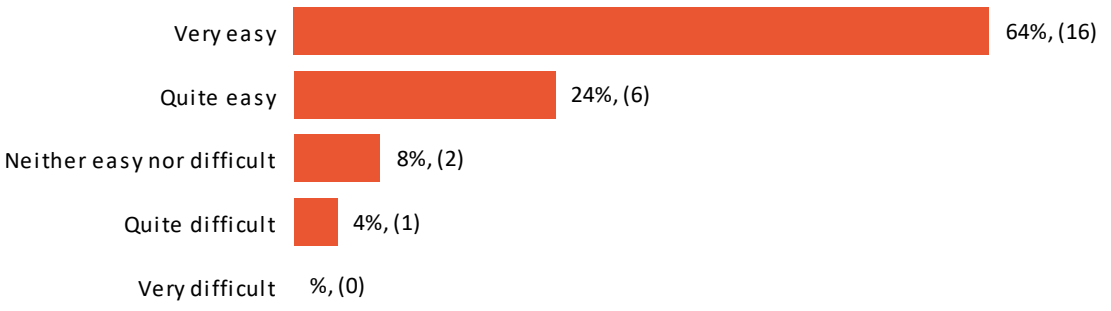
59% of respondents (48 out of 81) said that they would not know who to contact if they wanted to discuss any emotional concerns relating to their bleeding disorder.

Q46. Do you know who to contact if you want to discuss any emotional concerns relating to your bleeding disorder?

Based on 81 responses. Those responding, "Don't know/not sure" (15) excluded from percentage calculation.

Of the 25 respondents who had tried to make contact with the relevant team person to discuss their emotional concerns, 88% (22 out of 25 respondents) had found it very easy or quite easy, 1 person found it quite difficult, and 2 people gave a neutral response.

Q47. How easy or difficult is it for you to contact this person/team?



Based on 25 responses. Those responding, "I have not tried to contact them" (8) excluded from percentage calculation.

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3.7.5 Haemophilia Society

57% of respondents (46 out of 81) reported that someone at the treatment centre had told them about the Haemophilia Society and the support they offer.

Q48. Did someone at the treatment centre tell you about the Haemophilia Society and the support they offer?

Based on 81 responses. Those responding, "Don't know/can't remember" (14) excluded from percentage calculation.

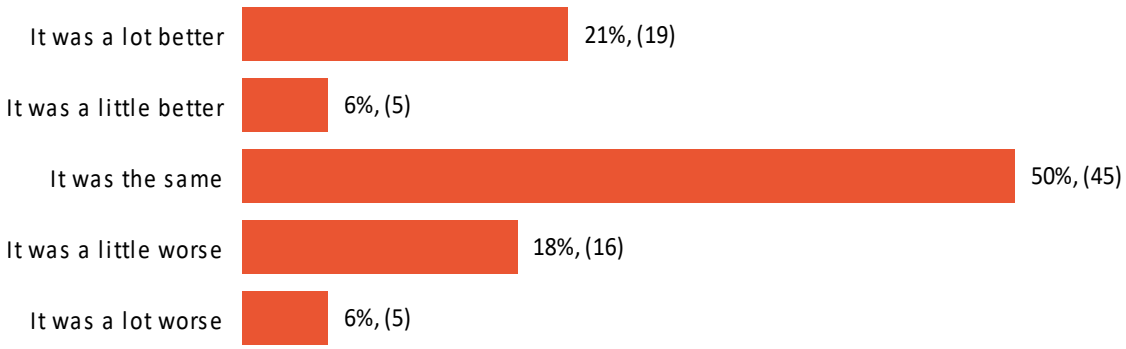
3.8 COVID-19 and Lockdown

For this section of the questionnaire, respondents were asked to think about the period when the UK was in lockdown from 23rd March 2020.

3.8.1 Care and treatment

50% of respondents (45 out of 90) said that the care and treatment they received for their bleeding disorder during lockdown was the same as their "normal" care and treatment. 27% (24 out of 90 respondents) said care was better and 23% (21 out of 90 respondents) said care was worse.

Q49. How did the care and treatment you received for your bleeding disorder compare to your 'normal' care and treatment?



Based on 90 responses. Those responding, "Don't know/not sure" (4) excluded from percentage calculation.

3.8.2 Treatment centre communication

41% of respondents (38 out of 93) said that their main treatment centre definitely communicated to them about how their care and treatment may be affected by COVID-19 lockdown. 27% of respondents (25 out of 93) said that this happened to a certain extent and 32% (30 out of 93 respondents) said it was not communicated.

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Q50. Did your main treatment centre communicate with you about how your care and treatment may be affected by COVID-19 and the subsequent lockdown?

Based on 93 responses. Those responding, "Don't know/not sure" (3) excluded from percentage calculation.

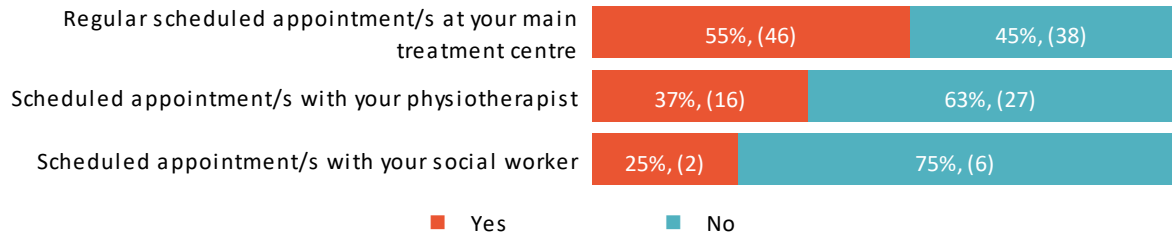
3.8.3 Scheduled appointments

55% of the respondents (46 out of 84) who had regular scheduled appointment/s at their main treatment centre said that these were cancelled or delayed. Ten people answered not applicable and were therefore excluded from the analysis.

37% of the respondents (16 out of 43) who had regular scheduled appointment/s with a physiotherapist said that these were cancelled or delayed. 46 people answered not applicable and were therefore excluded from the analysis.

2 of the 8 respondents who had a regular scheduled appointment/s with a social worker said that these were cancelled or delayed. 79 people answered not applicable and were therefore excluded from the analysis.

Q51. Were any of the following cancelled or delayed?



Those responding, "Not applicable" excluded from percentage calculations.

3.8.4 Emergency care

31% of respondents (30 out of 96) reported having an emergency relating to their bleeding disorder that required health care support during COVID-19/lockdown.

Of these respondents, the majority (83%, 25 out of 30) said that they were definitely able to get the right support for the emergency. 10% (3 out of 30 respondents) said that this happened to a certain extent and 7% (2 out of 30 respondents) said no, they were not able to get the right support.

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Q53. Were you able to get the right support for the emergency?

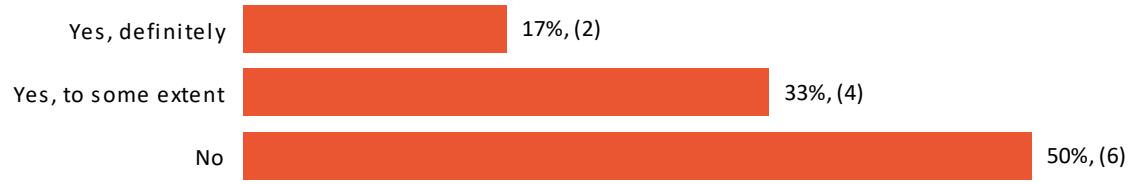
Based on 30 responses.

3.9 Females with a bleeding disorder

It was felt that it was important to try and understand more about some of the specific experiences of females with a bleeding disorder, particularly in regard to menstruation, fertility, pregnancy, and childbirth. However, as only 4 respondents reported having a period in the last year it is not possible to make robust conclusions from the majority of the questions.

Of the 12 females who felt it was applicable to them, just 2 said that they definitely had a conversation with a healthcare professional about how their bleeding disorder may affect fertility, pregnancy, and childbirth. 4 respondents said this had happened to some extent and 6 had not had a conversation.

M08. Have you ever had a conversation with a healthcare professional about how your bleeding disorder may affect fertility, pregnancy and childbirth?



Based on 12 responses. Those responding "Not applicable" (3) excluded from percentage calculation.

This Survey was carried out by Quality Health on behalf of Takeda and the Haemophilia Society.

For more information

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[1] The Haemophilia Society. *About the Haemophilia Society.* Available from: https://haemophilia.org.uk/about-the-haemophilia-society/#more-10410 [Accessed April 2021]

[2] O'Hara, J., Hughes, D., Camp, C. *et al* (2017). The cost of severe haemophilia in Europe: the CHESS study. *Orphanet J Rare Dis* 12, 106. https://doi.org/10.1186/s13023-017-0660-y

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