



2021 Bleeding Disorders Patient Experience Survey

Table of Detailed Results

Produced by Quality Health

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



Survey Results

This report sets out the results from the 2021 Bleeding Disorders Patient Experience Survey, ordered in exactly the same way as in the survey questionnaire provided to patients.

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

Fieldwork for this survey commenced on October 23rd, 2020 and went live on social media in December. This report has been produced using a dataset extracted from the Quality Health database following the close of fieldwork on February 5th, 2021. The timing of this fieldwork coincided with the COVID-19 pandemic. When responding to the survey, respondents were asked to consider the impact of living with their condition over the past year which, given the timing of the COVID-19 pandemic, meant that the virus could have had a confounding impact on responses. However, a specific section on COVID-19 was included to mitigate for this and to provide more specific information on the impact of COVID-19.

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

Throughout the data tables there are responses/percentages which are **italicised and marked with an asterisk**. **These percentages have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances, or they felt unable to give a definite answer.** For example, questions such as question 5a regarding the extent to which respondents have felt anxious, where those not answering ("Missing"), and those answering "Not applicable" have been excluded, or question 15 asking how easy or difficult was it for respondents to contact someone at their treatment centre, where those not answering ("Missing"), and those answering "I have not tried to contact them" have been excluded.

As only 4 people responded to questions M02 – M07, this data has been suppressed. This is to protect the anonymity of these people and because it is not possible to draw robust conclusions from such a small sub-set of respondents.

Limitations

This is a first of its kind national survey that has been run together with The Haemophilia Society looking at the experiences of people living with bleeding disorders, from condition management to achieving personal life goals. There are around 36,000 people in the UK living with a bleeding disorder. **The total number of respondents to this survey was 96.** Not all questions were applicable to each respondent, therefore some questions have limited data. **This data is further analysed in the accompanying report where the full limitations of this research are listed.**

Introduction

Q01. Who is filling in this survey?	ALL	
	Respondents	%
The person with the bleeding disorder	83	86%
A parent or guardian of the person with the bleeding disorder	11	11%
A friend, other relative or carer of the person with the bleeding disorder	0	0%
Both the person with the bleeding disorder and parent/guardian together	2	2%
Both the person with the bleeding disorder and friend/relative/carer together	0	0%
The person with the bleeding disorder with the help of a healthcare professional	0	0%
Missing	0	

Q02. Please tell us which bleeding disorder you have using the boxes below:	ALL	
	Respondents	%
Haemophilia A (without inhibitors)	52	54%
Haemophilia A (with inhibitors)	6	6%
Haemophilia B (without inhibitors)	10	10%
Haemophilia B (with inhibitors)	2	2%
Von Willebrand Disease	23	24%
Acquired haemophilia	3	3%
Missing	0	

Q03. Please tell us what classification your haemophilia diagnosis is:	ALL	
	Respondents	%
Mild	13	19%
Moderate	14	20%
Severe	43	61%
Don't know	0	0%
Missing	26	

Introduction (continued)

Q04. Please tell us what classification your von Willebrand Disease diagnosis is:	ALL	
	Respondents	%
Type 1	3	13%
Type 2	10	43%
Type 3	7	30%
Don't know	3	13%
Missing	73	

Quality of Life/Living with a bleeding disorder

Q05a. 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: I have felt anxious	ALL	
	Respondents	%
* <i>Not at all</i>	36	38%
* <i>A little</i>	35	37%
* <i>A lot</i>	24	25%
Not applicable	0	0%
Missing	1	

Q05b. 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: I have felt depressed	ALL	
	Respondents	%
* <i>Not at all</i>	47	50%
* <i>A little</i>	32	34%
* <i>A lot</i>	15	16%
Not applicable	0	0%
Missing	2	

Q05c. 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: I have worried about being a burden to others	ALL	
	Respondents	%
* <i>Not at all</i>	39	42%
* <i>A little</i>	29	32%
* <i>A lot</i>	24	26%
Not applicable	2	2%
Missing	2	

Q05d. 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: I have worried about my treatment	ALL	
	Respondents	%
* <i>Not at all</i>	40	43%
* <i>A little</i>	33	35%
* <i>A lot</i>	20	22%
Not applicable	1	1%
Missing	2	

Quality of Life/Living with a bleeding disorder (continued)

Q05e. 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: I have worried about my future health	ALL	
	Respondents	%
* <i>Not at all</i>	20	21%
* <i>A little</i>	45	47%
* <i>A lot</i>	31	32%
Not applicable	0	0%
Missing	0	

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: I have worried about my next bleed	ALL	
	Respondents	%
* <i>Not at all</i>	41	45%
* <i>A little</i>	35	38%
* <i>A lot</i>	15	16%
Not applicable	1	1%
Missing	4	

Q06a. 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: I have had difficulty walking	ALL	
	Respondents	%
* <i>Not at all</i>	35	38%
* <i>A little</i>	32	35%
* <i>A lot</i>	24	26%
Not applicable	3	3%
Missing	2	

Q06b. 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: I have had difficulty with self-care (e.g. dressing, such as putting on socks or reaching a collar, bathing, etc.)	ALL	
	Respondents	%
* <i>Not at all</i>	53	57%
* <i>A little</i>	31	33%
* <i>A lot</i>	9	10%
Not applicable	2	2%
Missing	1	

Quality of Life/Living with a bleeding disorder (continued)

Q06c. 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: I have had difficulty being independent	ALL	
	Respondents	%
* <i>Not at all</i>	59	63%
* <i>A little</i>	20	22%
* <i>A lot</i>	14	15%
Not applicable	2	2%
Missing	1	

Q06d. 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: I have had difficulty caring for my family/others	ALL	
	Respondents	%
* <i>Not at all</i>	52	63%
* <i>A little</i>	16	20%
* <i>A lot</i>	14	17%
Not applicable	12	13%
Missing	2	

Q06e. 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: I have had difficulty with physical activity/sports	ALL	
	Respondents	%
* <i>Not at all</i>	22	24%
* <i>A little</i>	39	43%
* <i>A lot</i>	30	33%
Not applicable	4	4%
Missing	1	

Q06f. 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: I have had difficulty with other hobbies/pastimes	ALL	
	Respondents	%
* <i>Not at all</i>	44	47%
* <i>A little</i>	35	38%
* <i>A lot</i>	14	15%
Not applicable	2	2%
Missing	1	

Quality of Life/Living with a bleeding disorder (continued)

Q06g. 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: I have had difficulty travelling (e.g. bus, train, flight or car)	ALL	
	Respondents	%
* <i>Not at all</i>	57	62%
* <i>A little</i>	22	24%
* <i>A lot</i>	13	14%
Not applicable	3	3%
Missing	1	

Q06h. 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: I have had difficulty leaving the house	ALL	
	Respondents	%
* <i>Not at all</i>	63	68%
* <i>A little</i>	18	20%
* <i>A lot</i>	11	12%
Not applicable	1	1%
Missing	3	

Q06i. 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: I have had difficulty with work (employment)	ALL	
	Respondents	%
* <i>Not at all</i>	46	66%
* <i>A little</i>	12	17%
* <i>A lot</i>	12	17%
Not applicable	25	26%
Missing	1	

Q06j. 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: I have had difficulty with studies/education	ALL	
	Respondents	%
* <i>Not at all</i>	48	69%
* <i>A little</i>	15	21%
* <i>A lot</i>	7	10%
Not applicable	24	26%
Missing	2	

Quality of Life/Living with a bleeding disorder (continued)

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: I have had difficulty going on holidays	ALL	
	Respondents	%
* <i>Not at all</i>	41	50%
* <i>A little</i>	25	30%
* <i>A lot</i>	16	20%
Not applicable	13	14%
Missing	1	

Q07. In the last year how often did you experience pain as a result of your bleeding disorder?	ALL	
	Respondents	%
* <i>Never</i>	17	18%
* <i>Rarely</i>	19	20%
* <i>Sometimes</i>	32	34%
* <i>Most of the time</i>	13	14%
* <i>Always</i>	13	14%
Don't know	0	0%
Missing	2	

Q08. Approximately how many times in the last year did you experience spontaneous bleeds which you have self-managed?	ALL	
	Respondents	%
0	34	37%
1	8	9%
2	7	8%
3	7	8%
4	6	6%
5	9	10%
6	6	6%
7	0	0%
8	1	1%
9	2	2%
10	5	5%
More than 10	8	9%
Missing	3	

Quality of Life/Living with a bleeding disorder (continued)

Q09. Approximately how many times in the last year did you experience spontaneous bleeds that have required an intervention?	ALL	
	Respondents	%
0	59	63%
1	10	11%
2	10	11%
3	6	6%
4	2	2%
5	2	2%
6	1	1%
7	1	1%
8	0	0%
9	1	1%
10	0	0%
More than 10	1	1%
Missing	3	

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.	ALL	
	Respondents	%
Strongly agree	27	28%
Agree	21	22%
Neither agree nor disagree	34	36%
Disagree	8	8%
Strongly disagree	5	5%
Missing	1	

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.	ALL	
	Respondents	%
Strongly agree	28	29%
Agree	44	46%
Neither agree nor disagree	10	10%
Disagree	10	10%
Strongly disagree	4	4%
Missing	0	

Quality of Life/Living with a bleeding disorder (continued)

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.	ALL	
	Respondents	%
Strongly agree	20	21%
Agree	31	33%
Neither agree nor disagree	31	33%
Disagree	9	10%
Strongly disagree	3	3%
Missing	2	

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.	ALL	
	Respondents	%
Strongly agree	29	31%
Agree	33	35%
Neither agree nor disagree	26	27%
Disagree	6	6%
Strongly disagree	1	1%
Missing	1	

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.	ALL	
	Respondents	%
Strongly agree	22	23%
Agree	28	29%
Neither agree nor disagree	12	13%
Disagree	26	27%
Strongly disagree	7	7%
Missing	1	

Quality of Life/Living with a bleeding disorder (continued)

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.	ALL	
	Respondents	%
Strongly agree	24	26%
Agree	40	44%
Neither agree nor disagree	15	16%
Disagree	7	8%
Strongly disagree	5	5%
Missing	5	

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.	ALL	
	Respondents	%
Strongly agree	5	5%
Agree	11	12%
Neither agree nor disagree	19	20%
Disagree	28	29%
Strongly disagree	32	34%
Missing	1	

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.	ALL	
	Respondents	%
Strongly agree	3	3%
Agree	9	9%
Neither agree nor disagree	21	22%
Disagree	31	33%
Strongly disagree	31	33%
Missing	1	

Quality of Life/Living with a bleeding disorder (continued)

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?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	36	38%
* <i>Yes, to some extent</i>	38	40%
* <i>No</i>	21	22%
Don't know/not sure	1	1%
Missing	0	

Q12. Overall, in the last year, how would you rate your quality of life whilst living with a bleeding disorder?	ALL	
	Respondents	%
0 - Very poor	2	2%
1	2	2%
2	10	11%
3	6	6%
4	4	4%
5	8	8%
6	6	6%
7	9	9%
8	16	17%
9	12	13%
10 - Very good	20	21%
Missing	1	

Access to care

Q13. Where is your main current place of treatment?	ALL	
	Respondents	%
Aberdeen	1	1%
Belfast - Adult's	4	5%
Belfast - Children's	1	1%
Birmingham (Queen Elizabeth)	3	3%
Bradford	2	2%
Bristol (Infirmary & Children's)	3	3%
Cambridge	3	3%
Canterbury	1	1%
Cardiff	2	2%
Dundee	1	1%
Edinburgh	1	1%
Exeter	1	1%
Glasgow (R.I.)	1	1%
Great Ormond Street	1	1%
Hammersmith Hospital, London	2	2%
Kettering	1	1%
Leeds	2	2%
Lewisham	1	1%
Liverpool (R. I.)	2	2%
Manchester (Adults)	6	7%
Manchester Children's	1	1%
Newcastle upon Tyne	4	5%
North Hampshire (Basingstoke)	1	1%
Oxford	6	7%
Royal Free	10	11%
Sheffield (Royal Hallamshire)	8	9%
Southampton	1	1%
St George's Hospital, London	3	3%
St Thomas' and Guy's Hospital	7	8%
Swansea	1	1%
Taunton / Yeovil	1	1%
The Royal London Hospital	2	2%
Torquay	1	1%
Truro	2	2%
Missing	9	

Access to care (continued)

Q14a. How would you rate your main current place of treatment on the following areas? Parking	ALL	
	Respondents	%
* <i>Excellent</i>	14	18%
* <i>Good</i>	17	21%
* <i>Average</i>	16	20%
* <i>Poor</i>	14	18%
* <i>Very poor</i>	19	24%
Not applicable	15	16%
Missing	1	

Q14b. How would you rate your main current place of treatment on the following areas? Ease of access via public transport	ALL	
	Respondents	%
* <i>Excellent</i>	19	25%
* <i>Good</i>	34	45%
* <i>Average</i>	15	20%
* <i>Poor</i>	5	7%
* <i>Very poor</i>	3	4%
Not applicable	20	21%
Missing	0	

Q14c. How would you rate your main current place of treatment on the following areas? Ease of access from main entrance to clinic or centre	ALL	
	Respondents	%
* <i>Excellent</i>	32	34%
* <i>Good</i>	33	35%
* <i>Average</i>	23	24%
* <i>Poor</i>	6	6%
* <i>Very poor</i>	0	0%
Not applicable	1	1%
Missing	1	

Access to care (continued)

Q14d. How would you rate your main current place of treatment on the following areas? Waiting area	ALL	
	Respondents	%
* <i>Excellent</i>	29	31%
* <i>Good</i>	37	39%
* <i>Average</i>	22	23%
* <i>Poor</i>	6	6%
* <i>Very poor</i>	1	1%
Not applicable	0	0%
Missing	1	

Q14e. How would you rate your main current place of treatment on the following areas? Other (please specify)	ALL	
	Respondents	%
* <i>Excellent</i>	4	40%
* <i>Good</i>	2	20%
* <i>Average</i>	0	0%
* <i>Poor</i>	0	0%
* <i>Very poor</i>	4	40%
Not applicable	25	71%
Missing	61	

Q15. In the last year, how easy or difficult was it for you to contact someone at your treatment centre?	ALL	
	Respondents	%
* <i>Very easy</i>	45	49%
* <i>Quite easy</i>	30	33%
* <i>Neither easy nor difficult</i>	10	11%
* <i>Quite difficult</i>	6	7%
* <i>Very difficult</i>	0	0%
I had not tried to contact them	5	5%
Missing	0	

Access to care (continued)

Q16. In the last year, did you have to attend A&E for an emergency visit relating to your bleeding disorder?	ALL	
	Respondents	%
Yes	21	22%
No	75	78%
Missing	0	

Q18. When you attended A&E, did the healthcare team you saw ask about your bleeding disorder?	ALL	
	Respondents	%
* <i>Always</i>	8	44%
* <i>Often</i>	4	22%
* <i>Sometimes</i>	2	11%
* <i>Rarely</i>	2	11%
* <i>Never</i>	2	11%
Don't know/can't remember	3	14%
Missing	75	

Q19. Do you feel that the healthcare team you saw in A&E understood how to treat/care for your bleeding disorder?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	4	21%
* <i>Yes, to some extent</i>	9	47%
* <i>No</i>	6	32%
Don't know/can't remember	2	10%
Missing	75	

Access to care (continued)

Q20. What outcomes did you experience when attending A&E?	ALL	
	Respondents	%
Given treatment in A&E	11	52%
Missing	10	
Sent elsewhere for treatment, e.g. Haematology Unit, Haemophilia Centre	11	52%
Missing	10	
Discharged without treatment	1	5%
Missing	20	
Don't know/can't remember	1	5%
Missing	20	

Q21. When you attended A&E, did you feel you got the treatment/care you needed?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	10	50%
* <i>Yes, to some extent</i>	7	35%
* <i>No</i>	3	15%
Don't know/can't remember	1	5%
Missing	75	

Involvement in treatment and care

Q22a. Please tell us if you know what the following treatment terms mean/stand for? SHL prophylaxis	ALL	
	Respondents	%
Yes, I know what this is	30	43%
No, I don't know what this is	40	57%
Missing	26	

Q22b. Please tell us if you know what the following treatment terms mean/stand for? SHL on demand	ALL	
	Respondents	%
Yes, I know what this is	32	45%
No, I don't know what this is	39	55%
Missing	25	

Q22c. Please tell us if you know what the following treatment terms mean/stand for? EHL prophylaxis	ALL	
	Respondents	%
Yes, I know what this is	28	39%
No, I don't know what this is	43	61%
Missing	25	

Q22d. Please tell us if you know what the following treatment terms mean/stand for? EHL on demand	ALL	
	Respondents	%
Yes, I know what this is	27	38%
No, I don't know what this is	44	62%
Missing	25	

Q22e. Please tell us if you know what the following treatment terms mean/stand for? Non-factor replacement therapy	ALL	
	Respondents	%
Yes, I know what this is	27	40%
No, I don't know what this is	41	60%
Missing	28	

Involvement in treatment and care (continued)

Q23. What was your main treatment plan in the last year?	ALL	
	Respondents	%
Regular treatment with standard half-life (SHL prophylaxis)	22	30%
Treatment with standard half-life only when a bleed is experienced (SHL on demand)	10	14%
Regular treatment with extended half-life (EHL prophylaxis)	11	15%
Treatment with extended half-life only when a bleed is experienced (EHL on demand)	2	3%
Non-factor replacement therapy	4	5%
Other (please specify below)	16	22%
Don't know	8	11%
Missing	23	

Q24. Have you had a conversation with your healthcare team about tailoring your treatment to your desired lifestyle?	ALL	
	Respondents	%
* Yes	41	77%
* No, but I would like this	9	17%
* No, I asked, but the person I spoke with did not want to engage in this conversation	3	6%
No, this has not been necessary	39	41%
Don't know/not sure	4	4%
Missing	0	

Q25. Who initiated this conversation?	ALL	
	Respondents	%
Me, the patient	14	35%
A parent or guardian	2	5%
My healthcare team	20	50%
Don't know/can't remember	2	5%
Other (please specify)	2	5%
Missing	56	

Involvement in treatment and care (continued)

Q26. What was the outcome of the conversation?	ALL	
	Respondents	%
Changed treatment regimen	18	44%
Missing	23	
Given access to additional support e.g. physiotherapy	10	24%
Missing	31	
Agreed to monitor treatment more closely	9	22%
Missing	32	
Nothing changed	9	22%
Missing	32	
Other (please specify)	4	10%
Missing	37	

Q27. Were you satisfied with the outcome of the conversation?	ALL	
	Respondents	%
* Yes	37	100%
* No	0	0%
Don't know/not sure	4	10%
Missing	55	

Q28. Over the last year, have you had regular reviews of your treatment plan?	ALL	
	Respondents	%
* Yes	65	70%
* No	28	30%
Don't know/can't remember	3	3%
Missing	0	

Involvement in treatment and care (continued)

Q29. In your last review, did you feel you had enough time to discuss your needs and treatment?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	49	75%
* <i>Yes, to some extent</i>	14	22%
* <i>No</i>	2	3%
Don't know/can't remember	0	0%
Missing	31	

Q30. How satisfied are you with how your current treatment regimen is working?	ALL	
	Respondents	%
* <i>Very satisfied</i>	46	48%
* <i>Satisfied</i>	32	33%
* <i>Neither satisfied nor dissatisfied</i>	12	13%
* <i>Dissatisfied</i>	4	4%
* <i>Very dissatisfied</i>	2	2%
Don't know/not sure	0	0%
Missing	0	

Q31. Do you feel comfortable raising any concerns you may have with your treatment and care?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	67	72%
* <i>Yes, to some extent</i>	18	19%
* <i>No</i>	8	9%
Don't know/not sure	1	1%
Not applicable	1	1%
Missing	1	

Q32a. Do the people you see at the treatment centre ever discuss the following with you? New treatment developments	ALL	
	Respondents	%
* <i>Yes</i>	53	64%
* <i>No</i>	30	36%
Don't know/can't remember	5	5%
Not applicable	7	7%
Missing	1	

Involvement in treatment and care (continued)

Q32b. Do the people you see at the treatment centre ever discuss the following with you? Switching treatment	ALL	
	Respondents	%
* Yes	45	57%
* No	34	43%
Don't know/can't remember	1	1%
Not applicable	16	17%
Missing	0	

Q32c. Do the people you see at the treatment centre ever discuss the following with you? Possibility of entering clinical trials	ALL	
	Respondents	%
* Yes	38	46%
* No	45	54%
Don't know/can't remember	6	6%
Not applicable	6	6%
Missing	1	

Q32d. Do the people you see at the treatment centre ever discuss the following with you? The use of technology such as apps to help with your treatment	ALL	
	Respondents	%
* Yes	37	49%
* No	39	51%
Don't know/can't remember	4	4%
Not applicable	16	17%
Missing	0	

Q32e. Do the people you see at the treatment centre ever discuss the following with you? Tailoring the frequency of treatment to your unique biological response	ALL	
	Respondents	%
* Yes	28	38%
* No	46	62%
Don't know/can't remember	5	5%
Not applicable	17	18%
Missing	0	

Involvement in treatment and care (continued)

Q32f. Do the people you see at the treatment centre ever discuss the following with you? Side effects of treatment	ALL	
	Respondents	%
* Yes	40	51%
* No	39	49%
Don't know/can't remember	4	4%
Not applicable	9	10%
Missing	4	

Q32g. Do the people you see at the treatment centre ever discuss the following with you? Tailoring treatment to your needs	ALL	
	Respondents	%
* Yes	56	68%
* No	26	32%
Don't know/can't remember	4	4%
Not applicable	9	9%
Missing	1	

Q32h. Do the people you see at the treatment centre ever discuss the following with you? How your treatment works	ALL	
	Respondents	%
* Yes	64	77%
* No	19	23%
Don't know/can't remember	6	6%
Not applicable	6	6%
Missing	1	

Q32i. Do the people you see at the treatment centre ever discuss the following with you? Pain management	ALL	
	Respondents	%
* Yes	50	66%
* No	26	34%
Don't know/can't remember	4	4%
Not applicable	15	16%
Missing	1	

Involvement in treatment and care (continued)

Q32j. Do the people you see at the treatment centre ever discuss the following with you? Emergency situations	ALL	
	Respondents	%
* Yes	64	75%
* No	21	25%
Don't know/can't remember	7	7%
Not applicable	3	3%
Missing	1	

Q32k. Do the people you see at the treatment centre ever discuss the following with you? Patient alert cards	ALL	
	Respondents	%
* Yes	55	65%
* No	30	35%
Don't know/can't remember	8	8%
Not applicable	2	2%
Missing	1	

Q33. Have you ever been asked by your current treatment centre to give your views on the quality of the care and treatment you receive?	ALL	
	Respondents	%
* Yes	50	56%
* No	40	44%
Don't know/can't remember	6	6%
Missing	0	

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?	ALL	
	Respondents	%
* Yes, always	28	30%
* Yes, most of the time	32	34%
* Yes, some of the time	26	28%
* No, never	7	8%
Don't know/not sure	3	3%
Missing	0	

Self-management

Q35. Do you manage your own treatment?	ALL	
	Respondents	%
Yes	73	78%
No	21	22%
Missing	2	

Q36. Overall, how easy do you find it to manage your own treatment?	ALL	
	Respondents	%
0 - Very difficult	0	0%
1	2	3%
2	4	5%
3	7	9%
4	3	4%
5	5	7%
6	2	3%
7	9	12%
8	11	15%
9	7	9%
10 - Very easy	24	32%
Missing	22	

Q37a. I find managing my own treatment... Acceptable	ALL	
	Respondents	%
Strongly agree	38	54%
Agree	27	38%
Neither agree nor disagree	3	4%
Disagree	2	3%
Strongly disagree	1	1%
Missing	25	

Self-management (continued)

Q37b. I find managing my own treatment... Stressful	ALL	
	Respondents	%
Strongly agree	3	4%
Agree	19	26%
Neither agree nor disagree	11	15%
Disagree	20	28%
Strongly disagree	19	26%
Missing	24	

Q37c. I find managing my own treatment... Convenient	ALL	
	Respondents	%
Strongly agree	32	45%
Agree	26	37%
Neither agree nor disagree	6	8%
Disagree	7	10%
Strongly disagree	0	0%
Missing	25	

Q37d. I find managing my own treatment... Restrictive	ALL	
	Respondents	%
Strongly agree	4	6%
Agree	15	21%
Neither agree nor disagree	17	24%
Disagree	15	21%
Strongly disagree	21	29%
Missing	24	

Self-management (continued)

Q37e. I find managing my own treatment... Empowering	ALL	
	Respondents	%
Strongly agree	25	35%
Agree	14	20%
Neither agree nor disagree	30	42%
Disagree	2	3%
Strongly disagree	0	0%
Missing	25	

Q38. Do your healthcare team give you enough information to allow you to manage your condition at home?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	59	80%
* <i>Yes, to some extent</i>	12	16%
* <i>No</i>	3	4%
Don't know/not sure	0	0%
Missing	22	

Additional Support

Q39a. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Lead haemophilia doctor (or lead haematologist)	ALL	
	Respondents	%
* <i>Excellent</i>	54	60%
* <i>Good</i>	24	27%
* <i>Average</i>	8	9%
* <i>Poor</i>	2	2%
* <i>Very poor</i>	2	2%
Not available	0	0%
Do not need	6	6%
Missing	0	

Q39b. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Lead haemophilia nurse (or lead haematology nurse)	ALL	
	Respondents	%
* <i>Excellent</i>	61	71%
* <i>Good</i>	17	20%
* <i>Average</i>	5	6%
* <i>Poor</i>	1	1%
* <i>Very poor</i>	2	2%
Not available	2	2%
Do not need	7	7%
Missing	1	

Q39c. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? On-call haemophilia specialist	ALL	
	Respondents	%
* <i>Excellent</i>	22	50%
* <i>Good</i>	13	30%
* <i>Average</i>	3	7%
* <i>Poor</i>	3	7%
* <i>Very poor</i>	3	7%
Not available	6	6%
Do not need	43	46%
Missing	3	

Additional Support (continued)

Q39d. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Bleeding disorders specialist nurses	ALL	
	Respondents	%
* <i>Excellent</i>	57	74%
* <i>Good</i>	15	19%
* <i>Average</i>	3	4%
* <i>Poor</i>	0	0%
* <i>Very poor</i>	2	3%
Not available	5	5%
Do not need	12	13%
Missing	2	

Q39e. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Clinical specialist physiotherapist	ALL	
	Respondents	%
* <i>Excellent</i>	46	71%
* <i>Good</i>	13	20%
* <i>Average</i>	2	3%
* <i>Poor</i>	1	2%
* <i>Very poor</i>	3	5%
Not available	8	9%
Do not need	18	20%
Missing	5	

Q39f. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Specialist psychology staff	ALL	
	Respondents	%
* <i>Excellent</i>	6	60%
* <i>Good</i>	2	20%
* <i>Average</i>	2	20%
* <i>Poor</i>	0	0%
* <i>Very poor</i>	0	0%
Not available	22	24%
Do not need	61	66%
Missing	3	

Additional Support (continued)

Q39g. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Specialist social workers	ALL	
	Respondents	%
* <i>Excellent</i>	4	40%
* <i>Good</i>	5	50%
* <i>Average</i>	1	10%
* <i>Poor</i>	0	0%
* <i>Very poor</i>	0	0%
Not available	22	23%
Do not need	62	66%
Missing	2	

Q39h. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Gynaecologist	ALL	
	Respondents	%
* <i>Excellent</i>	1	25%
* <i>Good</i>	1	25%
* <i>Average</i>	2	50%
* <i>Poor</i>	0	0%
* <i>Very poor</i>	0	0%
Not available	13	14%
Do not need	77	82%
Missing	2	

Q39i. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Pharmacist	ALL	
	Respondents	%
* <i>Excellent</i>	13	41%
* <i>Good</i>	10	31%
* <i>Average</i>	5	16%
* <i>Poor</i>	3	9%
* <i>Very poor</i>	1	3%
Not available	14	15%
Do not need	48	51%
Missing	2	

Additional Support (continued)

Q39j. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Dentist	ALL	
	Respondents	%
* <i>Excellent</i>	25	43%
* <i>Good</i>	21	36%
* <i>Average</i>	7	12%
* <i>Poor</i>	3	5%
* <i>Very poor</i>	2	3%
Not available	15	16%
Do not need	23	24%
Missing	0	

Q39k. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Occupational Therapist	ALL	
	Respondents	%
* <i>Excellent</i>	3	43%
* <i>Good</i>	2	29%
* <i>Average</i>	2	29%
* <i>Poor</i>	0	0%
* <i>Very poor</i>	0	0%
Not available	19	20%
Do not need	68	72%
Missing	2	

Q39l. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Your GP (the GP you see most frequently, not an out of hours service)	ALL	
	Respondents	%
* <i>Excellent</i>	21	30%
* <i>Good</i>	24	35%
* <i>Average</i>	16	23%
* <i>Poor</i>	5	7%
* <i>Very poor</i>	3	4%
Not available	5	5%
Do not need	21	22%
Missing	1	

Additional Support (continued)

Q39m. How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Other (please specify)	ALL	
	Respondents	%
* <i>Excellent</i>	1	14%
* <i>Good</i>	2	29%
* <i>Average</i>	3	43%
* <i>Poor</i>	0	0%
* <i>Very poor</i>	1	14%
Not available	2	6%
Do not need	27	75%
Missing	60	

Q40. In the last year were you offered physiotherapy appointments to help with your bleeding disorder?	ALL	
	Respondents	%
* <i>Yes</i>	51	80%
* <i>No, but I would have liked this</i>	13	20%
No, but I did not need this	27	28%
No, as I already had ongoing physiotherapy appointments	4	4%
Don't know/can't remember	0	0%
Missing	1	

Q41. How did you feel about the amount of time you had to wait for your physiotherapy appointments?	ALL	
	Respondents	%
* <i>I had to wait too long</i>	3	6%
* <i>I had to wait a little too long</i>	1	2%
* <i>The time I had to wait was about right</i>	44	92%
Don't know/not sure	3	6%
Missing	45	

Additional Support (continued)

Q42. In the last year were you given access to a social worker to assist with issues related to your bleeding disorder?	ALL	
	Respondents	%
* Yes	9	45%
* No, but I would have liked this	11	55%
No, but I did not need this	73	78%
No, as I already had access to a social worker	1	1%
Don't know/can't remember	0	0%
Missing	2	

Q43. How did you feel about the amount of time you had to wait for access to a social worker?	ALL	
	Respondents	%
* I had to wait too long	1	11%
* I had to wait a little too long	1	11%
* The time I had to wait was about right	7	78%
Don't know/not sure	1	10%
Missing	86	

Q44. In the last year were you given access to psychological support to assist with issues related to your bleeding disorder?	ALL	
	Respondents	%
* Yes	5	17%
* No, but I would have liked this	24	83%
No, but I did not need this	64	67%
No, as I already had access to psychological support	1	1%
Don't know/can't remember	1	1%
Missing	1	

Additional Support (continued)

Q45. How did you feel about the amount of time you had to wait for access to the psychological support?	ALL	
	Respondents	%
* <i>I had to wait too long</i>	1	25%
* <i>I had to wait a little too long</i>	0	0%
* <i>The time I had to wait was about right</i>	3	75%
Don't know/not sure	1	20%
Missing	91	

Q46. Do you know who to contact if you want to discuss any emotional concerns relating to your bleeding disorder?	ALL	
	Respondents	%
* <i>Yes</i>	33	41%
* <i>No</i>	48	59%
Don't know/not sure	15	16%
Missing	0	

Q47. How easy or difficult is it for you to contact this person/team?	ALL	
	Respondents	%
* <i>Very easy</i>	16	64%
* <i>Quite easy</i>	6	24%
* <i>Neither easy nor difficult</i>	2	8%
* <i>Quite difficult</i>	1	4%
* <i>Very difficult</i>	0	0%
I have not tried to contact them	8	24%
Missing	63	

Q48. Did someone at the treatment centre tell you about the Haemophilia Society and the support they offer?	ALL	
	Respondents	%
* <i>Yes</i>	46	57%
* <i>No</i>	35	43%
Don't know/can't remember	14	15%
Missing	1	

COVID-19 and Lockdown

Q49. How did the care and treatment you received for your bleeding disorder compare to your 'normal' care and treatment?	ALL	
	Respondents	%
* <i>It was a lot better</i>	19	21%
* <i>It was a little better</i>	5	6%
* <i>It was the same</i>	45	50%
* <i>It was a little worse</i>	16	18%
* <i>It was a lot worse</i>	5	6%
Don't know/not sure	4	4%
Missing	2	

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?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	38	41%
* <i>Yes, to some extent</i>	25	27%
* <i>No</i>	30	32%
Don't know/not sure	3	3%
Missing	0	

Q51a. Were any of the following cancelled or delayed? Regular scheduled appointment/s at your main treatment centre	ALL	
	Respondents	%
* <i>Yes</i>	46	55%
* <i>No</i>	38	45%
Not applicable	10	11%
Missing	2	

Q51b. Were any of the following cancelled or delayed? Scheduled appointment/s with your physiotherapist	ALL	
	Respondents	%
* <i>Yes</i>	16	37%
* <i>No</i>	27	63%
Not applicable	46	52%
Missing	7	

COVID-19 and Lockdown (continued)

Q51c. Were any of the following cancelled or delayed? Scheduled appointment/s with your social worker	ALL	
	Respondents	%
* Yes	2	25%
* No	6	75%
Not applicable	79	91%
Missing	9	

Q52. During this time did you have an emergency relating to your bleeding disorder that required health care support?	ALL	
	Respondents	%
Yes	30	31%
No	66	69%
Missing	0	

Q53. Were you able to get the right support for the emergency?	ALL	
	Respondents	%
Yes, definitely	25	83%
Yes, to some extent	3	10%
No	2	7%
Missing	66	

About you

Q54. Age Band (from 'What is your year of birth?')	ALL	
	Respondents	%
Under 16	6	7%
16 - 24	8	9%
25 - 34	8	9%
35 - 44	10	11%
45 - 54	14	15%
55 - 64	15	16%
65 - 74	24	26%
75 - 84	6	7%
85+	1	1%
Missing	4	

Q55. What gender are you?	ALL	
	Respondents	%
Male	74	77%
Female	22	23%
Trans	0	0%
Non-binary	0	0%
Other	0	0%
Prefer not to say	0	0%
Missing	0	

MPreQ. We would like to understand a little more about how bleeding disorders affect the lives of women and people who menstruate (have periods)... If these topics apply to you, or have applied to you in the past, please tick this box.	ALL	
	Respondents	%
Yes	15	100%
Missing	81	

Females with a Bleeding Disorder

M01. Did you have a period(s) in the last year?	ALL	
	Respondents	%
Yes	4	25%
No	12	75%
Missing	80	

M02a. Please select how much you agree with the following statements. Due to the bleeding I experience during my period... I avoid leaving the house	ALL	
	Respondents	%
* <i>Strongly agree</i>	-	-
* <i>Agree</i>	-	-
* <i>Neither agree nor disagree</i>	-	-
* <i>Disagree</i>	-	-
* <i>Strongly disagree</i>	-	-
Not applicable	-	-
Missing	-	

M02b. Please select how much you agree with the following statements. Due to the bleeding I experience during my period... I avoid going to work	ALL	
	Respondents	%
* <i>Strongly agree</i>	-	-
* <i>Agree</i>	-	-
* <i>Neither agree nor disagree</i>	-	-
* <i>Disagree</i>	-	-
* <i>Strongly disagree</i>	-	-
Not applicable	-	-
Missing	-	

Females with a Bleeding Disorder (continued)

M02c. Please select how much you agree with the following statements. Due to the bleeding I experience during my period... I avoid social situations	ALL	
	Respondents	%
* <i>Strongly agree</i>	-	-
* <i>Agree</i>	-	-
* <i>Neither agree nor disagree</i>	-	-
* <i>Disagree</i>	-	-
* <i>Strongly disagree</i>	-	-
Not applicable	-	-
Missing	-	-

M02d. Please select how much you agree with the following statements. Due to the bleeding I experience during my period... I avoid physical activities	ALL	
	Respondents	%
* <i>Strongly agree</i>	-	-
* <i>Agree</i>	-	-
* <i>Neither agree nor disagree</i>	-	-
* <i>Disagree</i>	-	-
* <i>Strongly disagree</i>	-	-
Not applicable	-	-
Missing	-	-

M03a. Please select the box which best describes to what extent these things have affected you, a result of your period. Tiredness/fatigue	ALL	
	Respondents	%
* <i>Significantly</i>	-	-
* <i>Moderately</i>	-	-
* <i>Slightly</i>	-	-
* <i>Not at all</i>	-	-
Don't know/not sure	-	-
Missing	-	-

Females with a Bleeding Disorder (continued)

M03b. Please select the box which best describes to what extent these things have affected you, a result of your period. Anaemia	ALL	
	Respondents	%
* <i>Significantly</i>	-	-
* <i>Moderately</i>	-	-
* <i>Slightly</i>	-	-
* <i>Not at all</i>	-	-
Don't know/not sure	-	-
Missing	-	-

M03c. Please select the box which best describes to what extent these things have affected you, a result of your period. Headaches	ALL	
	Respondents	%
* <i>Significantly</i>	-	-
* <i>Moderately</i>	-	-
* <i>Slightly</i>	-	-
* <i>Not at all</i>	-	-
Don't know/not sure	-	-
Missing	-	-

M03d. Please select the box which best describes to what extent these things have affected you, a result of your period. Pain	ALL	
	Respondents	%
* <i>Significantly</i>	-	-
* <i>Moderately</i>	-	-
* <i>Slightly</i>	-	-
* <i>Not at all</i>	-	-
Don't know/not sure	-	-
Missing	-	-

Females with a Bleeding Disorder (continued)

M03e. Please select the box which best describes to what extent these things have affected you, a result of your period. Heaviness of flow	ALL	
	Respondents	%
* <i>Significantly</i>	-	-
* <i>Moderately</i>	-	-
* <i>Slightly</i>	-	-
* <i>Not at all</i>	-	-
Don't know/not sure	-	-
Missing	-	-

M04. To what extent to you feel that your bleeding disorder impacts on your ability to manage and cope with your periods?	ALL	
	Respondents	%
* <i>Significantly</i>	-	-
* <i>Moderately</i>	-	-
* <i>Slightly</i>	-	-
* <i>Not at all</i>	-	-
Don't know/not sure	-	-
Missing	-	-

M05. On average how much do you think you have to spend on sanitary products to manage your period each month?	ALL	
	Respondents	%
Less than £10	-	-
£11 - £15	-	-
£16 - £20	-	-
£21 - £25	-	-
£26 - £30	-	-
More than £30	-	-
Missing	-	-

Females with a Bleeding Disorder (continued)

M06. How satisfied are you that healthcare professionals understand how your period affects your life?	ALL	
	Respondents	%
* <i>Very satisfied</i>	-	-
* <i>Satisfied</i>	-	-
* <i>Neither satisfied nor dissatisfied</i>	-	-
* <i>Dissatisfied</i>	-	-
* <i>Very dissatisfied</i>	-	-
Don't know/not sure	-	-
Missing	-	-

M07. How satisfied are you that healthcare professionals give you appropriate, regular advice and support to help you manage your periods?	ALL	
	Respondents	%
* <i>Very satisfied</i>	-	-
* <i>Satisfied</i>	-	-
* <i>Neither satisfied nor dissatisfied</i>	-	-
* <i>Dissatisfied</i>	-	-
* <i>Very dissatisfied</i>	-	-
Don't know/not sure	-	-
Missing	-	-

M08. Have you ever had a conversation with a healthcare professional about how your bleeding disorder may affect fertility, pregnancy and childbirth?	ALL	
	Respondents	%
* <i>Yes, definitely</i>	2	17%
* <i>Yes, to some extent</i>	4	33%
* <i>No</i>	6	50%
Not applicable	3	20%
Don't know/not sure	0	0%
Missing	81	

About You

Q56. Which of the following options best describes how you think of yourself?	ALL	
	Respondents	%
Heterosexual or Straight	84	89%
Gay or Lesbian	4	4%
Bisexual	1	1%
Other	1	1%
Prefer not to say	4	4%
Missing	2	

Q57. In addition to your bleeding disorder, do you have any of the following long-standing conditions?	ALL	
	Respondents	%
Deafness or severe hearing impairment	7	7%
Missing	89	
Blindness or partially sighted	2	2%
Missing	94	
A long-standing physical condition	16	17%
Missing	80	
A learning disability	3	3%
Missing	93	
A mental health condition	13	14%
Missing	83	
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	20	21%
Missing	76	

Q58. Is English your first language?	ALL	
	Respondents	%
Yes	92	97%
No	3	3%
Missing	1	

About You (continued)

Q59. To which of these ethnic groups do you belong?	ALL	
	Respondents	%
English / Welsh / Scottish / Northern Irish / British	90	94%
Irish	1	1%
Gypsy or Irish traveller	0	0%
Any other white background	2	2%
White and black Caribbean	1	1%
White and black African	0	0%
White and Asian	1	1%
Any other mixed background	0	0%
Indian	0	0%
Bangladeshi	0	0%
Chinese	1	1%
Any other Asian background	0	0%
Caribbean	0	0%
African	0	0%
Any other Black background	0	0%
Arab	0	0%
Any other ethnic group	0	0%
Missing	0	

EMAIL. I'm happy for The Haemophilia Society to contact me by: Email	ALL	
	Respondents	%
Yes	67	100%
Missing	29	

PHONE. I'm happy for The Haemophilia Society to contact me by: Phone	ALL	
	Respondents	%
Yes	22	100%
Missing	74	

About You (continued)

POST. Post	ALL	
	Respondents	%
Yes	20	100%
Missing	76	