Supplementary Material

Real-world experience of people with hemophilia A receiving turoctocog alfa pegol

(N8-GP): Results from a patient experience survey

Appendix 1 – Supplementary Methods

Recruitment

A random sampling methodology was used. Patients were selected based on having the characteristics required for the sample for the study. The target audience for this survey was difficult to access due to the fact that hemophilia A (HA) is a rare disease and turoctocog alfa pegol was launched relatively recently in some markets. Therefore, the recruitment of patients and carers was via a multichannel approach, utilizing the following methods:

- Agency panels of patients

- Referral from physicians treating HA (both HCPs via agency panels and desk recruitment e.g., contacting hospitals via formal letters or telephone calls)

- Referral from patients participating in the research

- Referral from patient associations

- Portugal: Associação Portuguesa de Hemofilia e de outras Coagulopatias Congénitas

- Private social media campaigns e.g., via private message to HCPs on LinkedIn

In all markets, patients and carers were signed up to their local recruitment agency before being contacted via telephone recruitment to assess their eligibility to take part. The research aimed to avoid the use of overly stringent and restrictive criteria in order to ensure that the study encompassed a broad cross-section of patients and carers for adolescents currently receiving N8-GP. Patients and carers were informed if they were able to take part in the survey

or if they did not meet the criteria (the specifics of why they did not meet the criteria were not disclosed).

Questionnaire

The questionnaire was manually developed by Lumanity with the input of the team at Novo Nordisk, as well as a patient living with HA and an HCP treating HA and prescribing N8-GP. Pilot interviews were carried out by the project research team at Lumanity in the form of a web-assisted tele-depth interview in order to ensure the questionnaire was accurate and easy to understand for the patients and carers. In the pilot, the respondent completed the live online survey and following completion of the survey, a member of the project research team interviewed the respondent to understand any areas of difficulty or misunderstanding. These areas were addressed prior to the launch of the study. The data from the pilot interview was not included in the final study results.

Data coding methodology

A thorough validation of fieldwork was essential to maintain the quality of the data generated. The team regularly monitored the data by means of on-the-ground validation (spot checks). These were completed by the supervisors daily throughout the fieldwork. Any inconsistencies, questionable responses, or other problems that cause concern regarding a respondent's data were considered to be a faulty interview. The scripted logic in the survey ensured respondents answered every question relevant to them so no questions contained missing data. If an error occurred in the survey link that caused missing data, this respondent would be recontacted and requested to answer the question again or the respondent would be replaced. However, in this survey this situation did not occur.

Initially, the data were cleaned and responses to open-ended questions were back-coded.
- A member of the project research team checked that the coding had been applied appropriately by the coding team.

- A member of the project research team at Lumanity was responsible for overseeing data capture and data cleaning.

- The final data were labelled appropriately along with key quality data such as serial number, date, time, and length of interview.

Once the data were processed and cleaned, the following steps were taken:

- Review of data at a base level: analysis of individual data points for each question.

- Identification of core areas of distinction or differentiation.

- Responses to open-ended questions (verbatim) were translated and coded manually by hand according to the code frame, which was checked and approved by a member of the core project team at Lumanity.

These aspects, together with key criteria (agreed in consultation with the Novo Nordisk team) such as age, time since diagnosis, duration of N8-GP treatment, etc. were used as cross-breaks to produce a complete set of tables for the data. Interim sets of tables were thoroughly checked with initial analysis on the data set to ensure the tables encompass all the relevant components for analysis.

Example of a back-coded, open-end answer

Q38b. Please describe why [Patient: you prefer your] [Carer: you think the person you care for prefers their] current treatment?

1. Example verbatim answered by a respondent:

    a. *"My current treatment is still an injection, however seeing almost <u>double the half-life</u> out of a product that can also <u>withstand temperatures of 103F</u> was extremely impressive and <u>improved my quality of treatment/life."</u>*

NET: Improved product characteristics

- **Subnet:** Longer half-life

    - **Code 8:** Longer half-life

        - Related verbatim: "double the half-life"
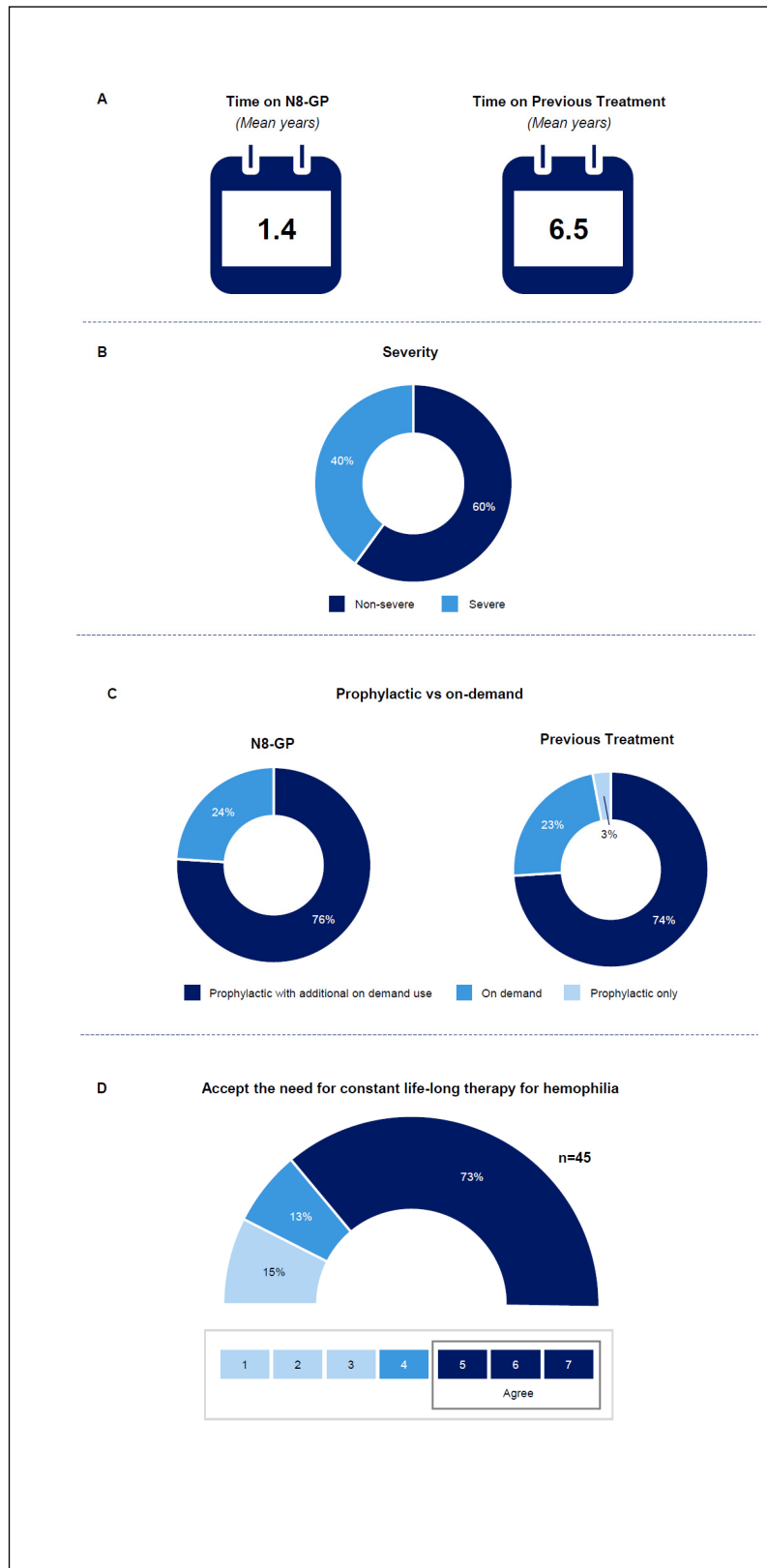
NET: More convenient product

- **Subnet:** Easier to store

    - **Code 1:** Drug can be stored at room temperature/ no need for refrigeration

        - Related verbatim: "withstand temperatures of 103F"

NET: Positive outcomes/ feelings

- **Subnet:** Improved quality of life

    - **Code 4:** Allows me to live a more active life/ improves quality of life

        - Related verbatim: "improved my quality of treatment/life.

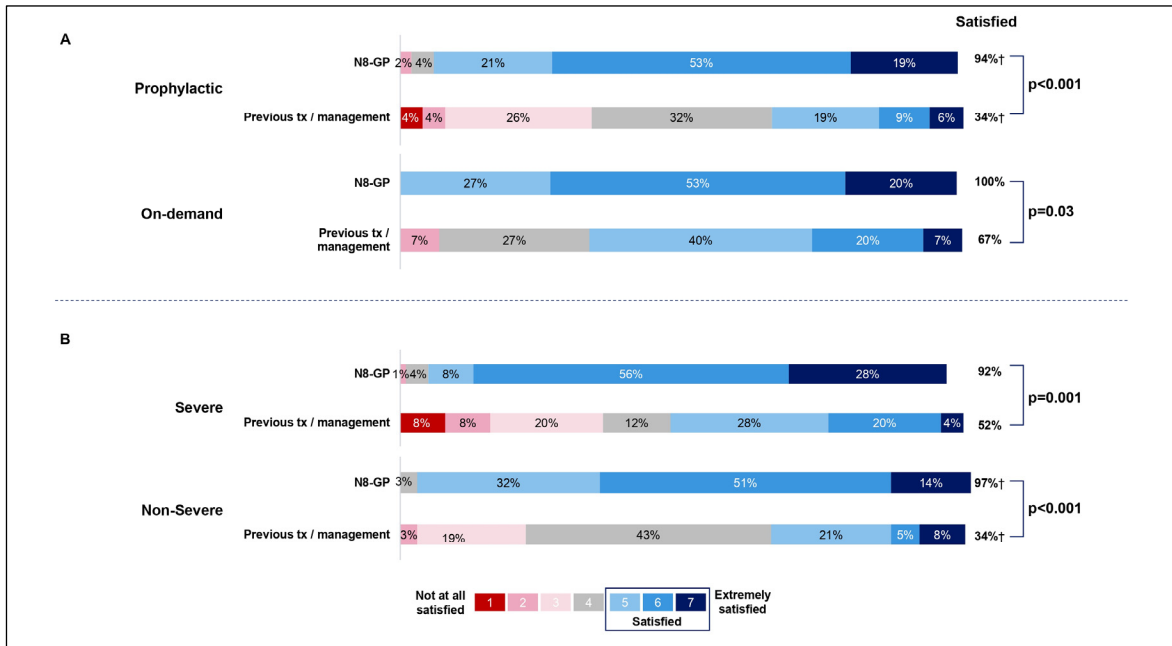**Figure S1: Time on N8-GP and previous treatment strategies**

(A) Mean time on N8-GP and previous Tx (S8b, S9).

(B) Severity status of patients. Non-severe: 60%, n=37; severe: 40%, n=25. (Q30).

(C) Mode of treatment with N8-GP and previous Tx. For N8-GP: 76%, n=47 on PPX; 24%, n=15 on-demand; previous Tx: 74%, n=44 PPX; 23%, n=14 on-demand; 3%, n=2 both treatments. (S8b, S9). Percentage of patients on prophylactic vs on-demand treatment.

(D) Statement related to acceptance of life-long therapy (Q25). Patients rating 5 to 7 are considered to be agreeing to the statement and represented as combined percentage (n=45, 73%). Base: All patients (n=62).
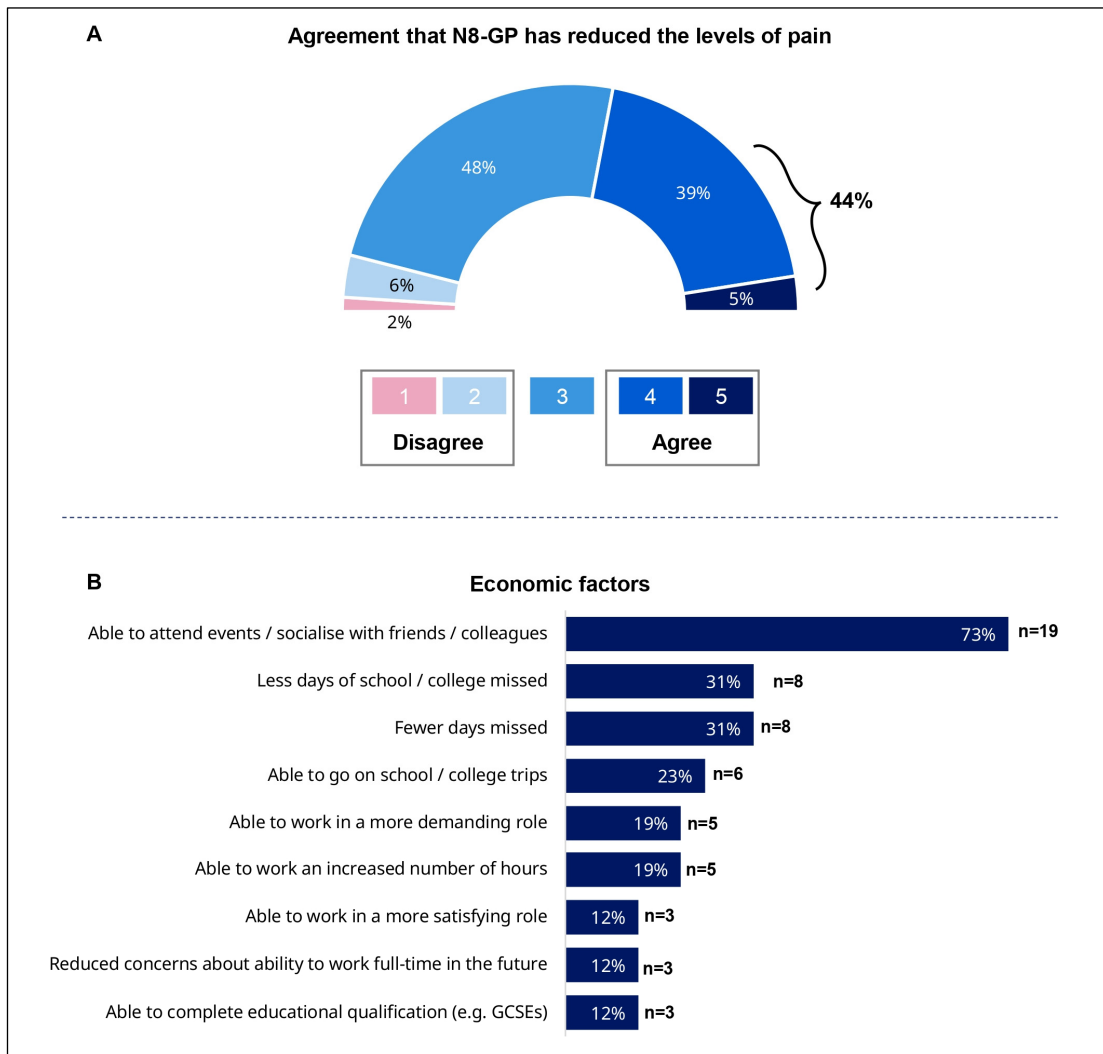
Figure S2: Treatment satisfaction in patient subgroups

(A) Percentage of patients on prophylaxis (n=46) and on-demand (n=15) treatment, satisfied with N8-GP and previous treatments measured on a 7-point scale (Q36). Patients rating 5 to 7 are considered satisfied with the treatment and are represented as combined percentage of patients satisfied with N8-GP. Prophylactic: N8-GP, n= 44, 94%; previous Tx, n=16, 34%. On-demand: N8-GP, n=15, 100%; previous Tx, n=10, 67%.

(B) Percentage of severe (n=25) and non-severe (n=37) patients, satisfied with N8-GP and previous treatments measured on a 7-point scale (Q36). Patients rating 5 to 7 are considered satisfied with the treatment and are represented as combined percentage of patients satisfied with N8-GP. Severe: N8-GP, n=23, 92%; previous Tx, n=7, 52%; non-severe: N8-GP, n=36, 97%; previous Tx, n=13, 34%. Tx: Treatment. †, indicate values are rounded.

Figure S3: N8-GP has a limited impact on economic factors.

A   **Agreement that N8-GP has reduced the levels of pain**

48%
39%
44%
6%
5%
2%

1	2		3		4	5
Disagree					**Agree**	

B   **Economic factors**

Able to attend events / socialise with friends / colleagues	73%	n=19
Less days of school / college missed	31%	n=8
Fewer days missed	31%	n=8
Able to go on school / college trips	23%	n=6
Able to work in a more demanding role	19%	n=5
Able to work an increased number of hours	19%	n=5
Able to work in a more satisfying role	12%	n=3
Reduced concerns about ability to work full-time in the future	12%	n=3
Able to complete educational qualification (e.g. GCSEs)	12%	n=3

(A) Agreement to the statement that N8-GP reduced the levels of pain experienced due to hemophilia (n=27, 42%). (Q39) Base: All participants (n=62).

(B) Limited impact on some of the aspects of days missed at college/work and ability to work (Q41, 42a/b). All patients where N8-GP has had a positive impact on education/work (n=26).

Supplementary Tables

Table S1: Country-specific participant recruitment

Participants	Total (n)	US	DE	IT	UK	ES	PT
Total (n)	62	7	11	25	3	11	5
Mild (5%-40% FVIII activity)	13	0	3	8	0	2	0
Moderate (1%-5% FVIII activity)	24	1	3	17	0	3	0
Severe (<1% FVIII activity)	25	6	5	0	3	6	5

DE, Germany; ES, Spain; IT, Italy; PT Portugal; UK, United Kingdom; US, United States; FVIII, factor VIII.

Table S2: List of previous treatments

Treatments	Total effective base (n;%)	Prophylaxis with additional extra doses given on-demand (n; %)	On-demand (n; %)	Only prophylaxis (n; %)
	60;100	44;76	14;24	2;3
Recombinant Factor VIII concentrates (Net n; %)	44;73	35;80	9;20	0;0
Novoeight®	12;20	9;75	3;25	0;0
Nuwiq®	9;15	8;89	1;11	0;0
Advate® / Helixate® / FS / NextGen® / Kogenate®	8;13	6;75	2;25	0;0
Elocta® / Eloctate®	7;11	6;86	1;14	0;0
Refacto® / Xyntha® AF / AF	5;8	4;80	1;20	0;0
Jivi®	3;5	2;67	1;33	0;0
Plasma-derived Factor VIII concentrates (Net)	12;20	8;67	4;33	0;0
Emoclot® / D.I.	4;7	2;50	2;50	0;0
Octanate®	3;5	3;100	0;0	0;0
Fanhdi®	2;3	2;100	0;0	0;0
Beriate®	1;2	0;0	1;100	0;0
Optivate®	1;2	0;0	1;100	0;0
Don't know	1;2	1;100	0;0	0;0
Bypassing agents (Net)	1;2	0;0	0;0	1;100
NovoSeven®	1;2	0;0	0;0	1;100

Hemlibra®	2;3	0;0	0;0	2;100
Other non-factor therapy	1;2	1;100	0;0	0;0
Other recombinant factor VIII concentrates	5;8	4;80	1;20	0;0
Other plasma-derived factor VIII concentrate	2;3	2;100	0;0	0;0

The table is based on survey question Q33a on treatment received prior to starting N8-GP.

Percentages (%) with corresponding number of participants (n) on various previous therapies for hemophilia are presented. Effective base=60 (represents combined previous treatments for all categories in hemophilia therapy)

Table S3: Reasons started on N8-GP

Reason	Responses (n; %)
Less frequent injections	40;65
Improve QoL	37;60
More convenient treatment	33;53
Better joint protection & stable joint health	27;44
Decrease # of bleeds &/or less worries	24;39
Few side effects	21;34
More confidence participating in PA	16;26
Wanted higher trough levels	7;11
Product with no human plasma/protein	6;10
Informed about trial results & wanted to try	6;10
Part of clinical trial & continued after	3;5
Longer half-life	1;2
Storage can be done above 30°C	1;2
Previous treatment was not working well	1;2

The table is based on the survey question Q31a on reasons for starting on N8-GP treatment.

Table S4: Quality-of-life score in participant groups

Participant group	QoL score		P value
	Prior to starting N8-GP	N8-GP	
Adult	69.1	78.2	<0.001
Caregiver	57.5	65.6	<0.001
Non-severe	62.03	70.41	<0.001
Severe	71.6	81.2	0.001
Prophylaxis	64.89	75.11	<0.001
On-demand	69	73.67	0.008

QoL score currently and prior to N8-GP between patient groups: adult and caregivers; non-severe and severe; prophylaxis and on-demand. (adults n=46; caregivers, n =16). (non-severe, n=37; severe, n=25). (prophylaxis, n=47; on-demand, n=15) (Q26 & Q35).

Table S5: Expectation for storage at room temperature and countries achieved

Country	Expectation from N8-GP (%)	Achieved by N8-GP (%)
UK	100	67
Spain	73	55
US	71	43
Italy	64	88
Germany	64	64
Portugal	40	20

The table is based on survey questions Q32b and Q40 on 'convenience' factors for the ability

to store at room temperature.

Table S6: Expression of patients' thoughts on convenience with N8-GP

Verbatim responses from participants
"Because I can store the drug at room temperature; it limits me to a much lower extent in my day-to-day life." **Adult patient, IT**
"I can store the product in a simple way, without the need of a fridge." ***Carer, IT***
"I can bring it with me even though the weather is warm outside; I do not need to store it in a cool place." ***Adult patient, IT*** *"My current treatment is still an injection, however seeing almost double the half-life out of a product that can also withstand temperatures of 103F was extremely impressive and improved my quality of treatment/life."* ***Adult patient, US***
"It is more portable with being able to tolerate higher temperatures." ***Adult patient, US***
"When planning a holiday or other longer trips, not having to waste a lot of thought on the medication in terms of cooling, storing and administration."

The responses are based on survey question Q32a (Thinking about treatments for hemophilia A, what does the word 'convenience' mean to you in this context)

Appendix 2 – Survey questionnaire

Screener

S1. ASK ALL

Single code

Are you, or any member of your household, employed by the pharmaceutical industry on a full-time or consultancy basis, or is any member of your household employed by a communication or advertising industry related to pharmaceutical products?

Please select one option only.

1. Yes **– THANK AND CLOSE**

2. No

S2. ASK ALL

Numeric

How old are you?

Please enter your age in the box.

1. Years

Range 0-99

THANK AND CLOSE IF <16 [18 for JAPAN ONLY] OR >80

S3. ASK ALL

Single code

Which of the following best describes your personal situation?

Please select one option only.

1. I have been diagnosed by a medical professional with hemophilia A

2. I have been diagnosed by a medical professional with hemophilia A with inhibitors

3. I am the parent / caregiver to someone who has been diagnosed with hemophilia A

4. I am the parent / caregiver to someone who has been diagnosed with hemophilia A with inhibitors

5. None of the above

6. I am not sure

THANK AND CLOSE IF CODE 1 OR 3 NOT SELECTED

IF CODE 3 SELECTED AND <18 @ S2, THANK AND CLOSE

IF CODE 1 SELECTED, PROCEED AS PATIENT. IF CODE 3 SELECTED, PROCEED AS CARER

S3b. ASK IF PATIENT AND <18 AND NOT JAPAN 10

Single code

Has consent to participate in the research been provided by a parent or guardian?

1. Yes – Recruitment agency to ensure the necessary consent forms have been filled in before continuing

2. No

THANK AND CLOSE IF CONSENT IS NOT RECEIVED

S4. ASK IF CARER

Numeric

What is the age of the person you care for?

3. Years

THANK AND CLOSE IF <12 OR ≥18

IF ≥18 YEARS OLD: Recruitment agency to follow-up to see if patient would be interested in seeing if they are eligible to participate.

S5. ASK ALL

Numeric

How long ago [PATIENT: were you] [CARER: was the person you care for] clinically diagnosed with hemophilia A?

Please enter the number of years and/or months in the boxes.

1. Years

2. Months

Years: Range 0-age (Patient: S2, CARER: S4)

Months: 0-11

THANK AND CLOSE IF MONTHS <6 & YEARS = 0

S6. ASK IF CARER

Single code

Which of the following describes your relationship with the patient with hemophilia A that you care for / support? I am the…

Please select one option only.

1. Mother

2. Father

3. Sibling

4. Other relative

5. Partner / Spouse

6. Friend

7. Unpaid carer (please specify) (INSERT OE)

8. Healthcare professional **– THANK AND CLOSE**

9. Paid carer **– THANK AND CLOSE**

S7a. ASK IF CARER

Single code

Do you live in the same household as the person that you care for?

Please select one option only.

1. Yes

2. No

S7b. ASK IF CARER & CODE 2 SELECTED @ S7a (Does not live in same household)

Numeric

How many hours on average do you spend a week providing care?

Please enter the number of hours in the box.

1. Hours

Range 0-168

THANK AND CLOSE IF <25

S8a. ASK ALL

Multicode – Randomise

Which of the following products [Patient: are you] [Carer: is the person you care for] currently

prescribed to manage [Patient: your] [Carer: their] hemophilia A?

Please select [Patient: *your*] [Carer: *the*] *current treatment(s).*

1. Advate® [Hide in CH & AT & JP & ES: **/** [Hide in IT: **Helixate**® [HIDE in PT: **FS**]] [PT only:

NextGen]] [Hide in CH & JP & ES: **/ Kogenate**® Hide in IT: **FS**] **/ Kovaltry**® **/** [Hide in CH &

AT& JP: **Recombinate**® Hide in IT: **rAHF**]

2. Hide in PT, IT & AT: **Adynovate**® **/**] **Adynovi** ®

3. Afstyla ®

4. Elocta® [Hide in PT & IT: **/ Eloctate**®]

5. Esperoct® **– Must select to continue**

6. Jivi ®

7. Refacto® [IT only: **AF**] [Hide in PT & IT: **/ Xyntha**® **AF**]

8. Novoeight®

9. Nuwiq®

50. Hemlibra® – Can be selected with another treatment, all others are single code **–**

SCREEN OUT

61. NovoSeven® - Can be selected with another treatment, all others are single code

98. Other – Anchor

99. Not currently treated – Anchor

S8b. ASK ALL

Single code

Which of the following best describes when [Patient: you use your] [Carer: the person you care for uses their] current treatment (Esperoct®)?

Throughout the remainder of the survey, we will refer to 'Esperoct®' as [Patient: your current treatment] [Carer: the current treatment of the person you care for].

Please select one option only.

1. Prophylactic treatment (regular treatment to prevent or reduce the number of bleeds). Additionally, extra doses may be given on-demand during a bleed

2. Only during a bleed as an 'on-demand' treatment

S9. ASK ALL

Numeric

How long ago [Patient: were you] [Carer: was the person you care for] first prescribed their current treatment (Esperoct®)?

Please enter the number of years and/or months in the boxes.

1. Years

2. Months

Range years: 0-S5

Months: 0-11

S9 must be less than or equal to S5

If answer is 4-8 years, please show soft error message: "You have entered that you have been on your current treatment Esperoct® for [pipe answer]. Please review your answer. If this is correct please continue"

If answer is >8 years screenout

S10. ASK PATIENTS ONLY

Single code

Could you please confirm that if selected to proceed with the survey, you will have access to a computer / laptop / desktop to complete the survey? **Please note tablets / iPads or other electronic devices will not be suitable**

1. Yes

2. No – THANK AND CLOSE

Section 1: Validated PRO – EQ-5D (~2 mins)

Q1. ASK IF PATIENT

Single code

Please select the ONE box that best describes your health TODAY.

MOBILITY

1. I have no problems in walking about

2. I have slight problems in walking about

3. I have moderate problems in walking about

4. I have severe problems in walking about

5. I am unable to walk about

Q2. ASK IF PATIENT

Single code

Please select the ONE box that best describes your health TODAY.

SELF-CARE

1. I have no problems washing or dressing myself

2. I have slight problems washing or dressing myself

3. I have moderate problems washing or dressing myself

4. I have severe problems washing or dressing myself

5. I am unable to wash or dress myself

Q3. ASK IF PATIENT

Single code

Please select the ONE box that best describes your health TODAY.

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

1. I have no problems doing my usual activities

2. I have slight problems doing my usual activities

3. I have moderate problems doing my usual activities

4. I have severe problems doing my usual activities

5. I am unable to do my usual activities

Q4. ASK IF PATIENT

Single code – AE FLAG FOR LACK OF EFFICACY, CURRENT TREATMENT =

ESPEROCT (NN PRODUCT) AND CODE 2-5 SELECT AT Q4

Please select the ONE box that best describes your health TODAY.

PAIN / DISCOMFORT

1. I have no pain or discomfort

2. I have slight pain or discomfort **– AE FLAG**

3. I have moderate pain or discomfort **– AE FLAG**

4. I have severe pain or discomfort **– AE FLAG**

5. I have extreme pain or discomfort **– AE FLAG**

Q5. ASK IF PATIENT

Single code – AE FLAG, CURRENT TREATMENT = ESPEROCT (NN PRODUCT) AND CODE 2-5 SELECT AT Q5

Please select the ONE box that best describes your health TODAY.

ANXIETY/ DEPRESSION

1. I am not anxious/depressed

2. I am slightly anxious/depressed **– AE FLAG**

3. I am moderately anxious/depressed **– AE FLAG**

4. I am severely anxious/depressed **– AE FLAG**

5. I am extremely anxious/depressed **– AE FLAG**

Q6. ASK IF PATIENT

Numeric

We would like to know how good or bad your health is TODAY

The scale is numbered from 0 to 100

100 means best health you can imagine

0 means worst health you can imagine

Please slide the scale to mark where your health is today

Section 2: Attitudes towards Hemophilia (~3 mins)

Q21. ASK ALL

Multicode - select 3, Randomise

Please select the top 3 words [Patient: you] [Carer: **the person you care for**] would MOST

often use to describe [Patient: your] [Carer: their] experience with hemophilia?

Please select 3 options.

1. Sad

2. Burdened

3. Worried

4. Relaxed

5. Free/unbounded

6. Happy

7. Frustrated / angry

8. Lonely / isolated

9. Optimistic / hopeful

10. Overwhelmed

11. Resilient / strong

12. Acceptance

13. Hard work

Q22. ASK ALL

Single select per row, 1-4 scale

Next, we would like to understand how hemophilia impacts [Patient: your] day-to-day life [Carer: of the person you care for]. How would you rate the impact on each statement below?

Please answer on a scale from 1 to 4, where 1 is "No negative impact" and 4 is "Significant negative impact".

Columns

1. No negative impact

2. Minor negative impact

3. Moderate negative impact

4. Significant negative impact

Rows - Randomise

1. Feelings of self-worth and self-confidence

2. Levels of stress and anxiety

3. Social life / relationships

4. Amount and quality of sleep

5. Education / work

6. Ability to undertake physical activity / exercise

7. Ability to go on holiday / travel

8. Autonomy or independence to live like a person without hemophilia

9. Day-to-day routine / activities

10. Overall quality of life - Anchor

Q22b. ASK ALL

1-7 scale

Thinking about the best and worst [Patient: your hemophilia] [Carer: the hemophilia of the person you care for] has been, how would you describe [Patient: your] [Carer: their] hemophilia **currently**?

Please select your answer on the scale.

1. 1 – The worst

2. 2

3. 3

4. 4

5. 5

6. 6

7. 7 – The best

Q23. ASK ALL

Single code

Which of the following best describes the highest level of daily activities [Patient: you are] [Carer: the person you care for is] **currently** able to do.

Please select one option only.

1. No activity

2. Light activity (e.g. household chores, slow walking, mild stretching)

3. Moderate activity (e.g., brisk walking, riding a bike, dancing, recreational swimming)

4. Vigorous activity (e.g., jogging / running, skipping rope, aerobics)

5. Very vigorous activity (e.g., lifting heavy weights, sprinting up hills, contact sports e.g. soccer)

Q24. ASK IF PATIENT

Multi code - Randomize

What is your current employment status?

Please select all that apply.

1. Working full time

2. Working part time

3. Self-employed / contract worker

4. Retired

5. Unemployed

6. Volunteering

7. Full-time carer

8. Part-time student

9. Full-time student

10. Receiving disability financial assistance

11. Other – Anchor

Cannot select code 1-5 together, Cannot select code 8-9 together, Cannot select code 1, 7 and 9 together

Q25. ASK ALL

Single select per row, 1-7 scale – Randomise statements 18

Please take a look at the contrasting statements below. Using the 1-7 scale below, please indicate the statements you [Carer: think the person you care for would] most closely agree with.

a) 1: My hemophilia is fully in control of me …. 7: I am fully in control of my hemophilia.

b) 1: I think about my hemophilia all the time…7: There are times I am able to forget about my hemophilia.

c) 1: I try to limit the activities I do because of my hemophilia…7: I try to participate in as many activities as I can despite my hemophilia

d) 1: I rely on my doctor for information about hemophilia…7: I regularly seek out information about hemophilia independently from my doctor.

e) 1: My family do not understand enough about my hemophilia…7: My family are very knowledgeable about my hemophilia.

f) 1: My close friends do not understand enough about my hemophilia…7: My close friends are very knowledgeable about my hemophilia -anchor with statement e and g.

g) 1: My [If Carer OR If patient & code 8-9 @ Q24 school friends] [If both /] [If patient & code 1-3 or 6 @ Q24: co-workers] do not understand enough about my hemophilia…7: My [If Carer OR If patient & code 8-9 @ Q24 school friends] [If both /] [If patient & code 1-3 or 6 @ Q24: co-workers] friends are very knowledgeable about my hemophilia -anchor with statement e and f, Show if Carer OR If patient & code 1-3,6 or 8-9 @ Q24.

h) 1: It is hard to understand what I need to do to lead a normal life with my hemophilia….7: I understand what I need to do to lead a normal life with my hemophilia.

i) 1: I am very distressed by my hemophilia…7: I have found peace in living with my hemophilia.

j) 1: I find it difficult accepting the need for constant life-long therapy for my hemophilia…7: I accept the need for constant life-long therapy for my hemophilia.

k) 1: I need to tell people about my hemophilia …7: I don't have to tell people about my hemophilia.

l) 1: I have to take time to plan my activities in day-to-day life due to my hemophilia…7: I am able to do activities in day-to-day life without planning due to my hemophilia.

Q26. ASK ALL

Numeric

Assuming an average person without hemophilia's quality of life is 100, where do you perceive [Patient: your quality of life] [Carer: the quality of life of the person you care for] to be?

If you perceive that it is worse than an average person without hemophilia, please enter a number less than 100. If you perceive it is better, please enter a value over 100.

Range 0-200

Section 3: Current and previous treatment perceptions (~9 mins)

Qintro3.1. SHOW ALL

Text

Next, we'd like to understand more about the treatments [Patient: you have] [Carer: the person you care for has] received for hemophilia A.

Q30. ASK ALL

Single code

When diagnosed with hemophilia A by a healthcare professional, which of the following severities [Patient: were you] [Carer: was the person you care for] diagnosed with?

Please select one option only.

1. Mild (5-40% of normal amount of clotting factors in blood)

2. Moderate (1-5% of normal amount of clotting factors in blood)

3. Severe (Less than 1% of normal amount of clotting factors in blood)

4. I don't know

Q31a. ASK ALL

Multicode – Randomise – Do not allow statement 1 and 2 to be selected together

What were the reasons [Patient: you] [Carer: the person you care for was] started on [Patient: your] [Carer: their] **current treatment**?

Please select all that apply.

1. Was part of the clinical trial and continued with the treatment after the trial finished

2. Informed about the trial results and wanted to try it

3. Wanted a treatment with few side effects

4. Wanted a product with no human plasma/protein

5. Wanted a product that allows participation in physical activity with more confidence

6. Wanted a more convenient treatment

7. Wanted a treatment offering better joint protection and stable joint health

8. Wanted to decrease number of bleeds and / or have less worries about bleeding

9. Wanted to improve quality of life

10. Wanted less frequent injections

11. Wanted higher trough levels

12. Other (please specify) Insert OE box, anchor **– MONITOR FOR AES**

99. I don't know / doctor did not say – anchor, exclusive code

Q31b. ASK ALL

Ranking – Randomise, must rank 3-5

When [Patient: you] [Carer: the person you care for was] started on [Patient: your] [Carer:

their] **current treatment** for Hemophilia what did [Patient: you] [Carer: they] **most hope to**

achieve?

Please rank at least 3 and up to five items from the below list.

1. Higher trough levels to reduce the risk of bleeds

2. Lower number of bleeds per year (annualised bleeding rate)

3. Less frequent injections

4. Easy / quick treatment set-up

5. Increased storage flexibility of treatment

6. Less risk of adverse events

7. Able to use as an 'on-demand' treatment during a bleed

8. Reduce pain caused by hemophilia

9. Provide joint protection andimprove joint health

10. Improve quality of life

11. Reduce impact on daily living activities

12. Increase confidence in doing physical activity

13. Improve mental health and reduce stress and anxiety caused by hemophilia

99. Other hope not listed (please specify)- MONITOR FOR AES

Q32a. ASK ALL - MONITOR FOR AES

Open end

Thinking about treatments for hemophilia A, what does the word 'convenience' mean to you in this context?

Please enter as much detail as possible.

Insert open end text box. Minimum 10 characters

Q32b. ASK ALL

Multicode - Randomise

Which of the following, if any, do you feel best describes 'convenience' when thinking about treatments for hemophilia A?

Please select as many as apply.

1. Faster administration

2. Less frequent injections

3. Simpler dosing schedule

4. Easy / quick treatment set-up

5. Ability to store treatment at room temperature

6. Ability to use as an 'on-demand' treatment during a bleed

7. Easy way of taking treatment (i.e. administration method e.g. oral tablet, injection, IV)

8. Small treatment kit bag for when travelling

99. None of the above – exclusive code, anchor

Q33a. ASK ALL

Multi code

Earlier you confirmed that [Patient: you were] [Carer: the person you care for was] taking Esperoct as [Patient: your] [Carer: their] current treatment for hemophilia A.

What treatment(s) [Patient: were you] [Carer: was the person you care for] receiving immediately prior to their current treatment?

Please select the treatments [Patient: *you were*] [Carer: *the person you care for was*] *receiving immediately prior to* [Patient: *your*] [Carer: *their*] *current treatment.*

Rows – Show category headings, randomise within categories

Codes highlighted in pale blue are shown at S8a, please ensure code names and numbers align.

GERMANY ONLY: HIDE ALL CODES EXCEPT CODE 96, 97, 98, 99, 100 and 101. Coders: Please use logic instructions in Germany to refer to available treatments

Recombinant factor VIII concentrates		
01	**Advate**® [Hide in CH & AT & JP & ES: **/** [Hide in IT: **Helixate**® [HIDE in PT: **FS**]] [PT only: **NextGen**®]] [Hide in CH & JP & ES: **/ Kogenate**® Hide in IT: **FS**] **/ Kovaltry**® **/** [Hide in CH & AT& JP: **Recombinate**® Hide in IT: **rAHF**]	
02	[Hide in PT, IT & AT: **Adynovate**® **/**] **Adynovi**®	
03	**Afstyla** ®	
04	**Elocta**® [Hide in PT & IT: **/ Eloctate**®]	
05	**Esperoct**® **– NOVO NORDISK PRODUCT**	Do not show code at this question
06	**Jivi**®	
07	**Refacto**® [IT only: **AF**] [Hide in PT & IT: **/ Xyntha**® **AF**]	Hide in JP
08	**Novoeight**® **– NOVO NORDISK PRODUCT**	
09	**Nuwiq** ®	
96	[Hide in Germany: Other] recombinant factor VIII concentrate (please specify) **– MONITOR FOR AES**	Anchor, insert OE box

Plasma-derived factor VIII concentrates		
13	**Alphanate** ®	
15	**Beriate**®	
17	**Conco-eight-HT** ®	
18	**Confact F** ®	
19	**Cross Eight M** ®	
20	**Emoclot**® [Hide in IT: **D.I.**]	
21	**Factane** ®	
23	**Faktor VIII SDH Intersero** ®	
24	**Fanhdi**®	
27	**Haemate P**®	
28	**Haemoctin**® [Hide in IT: **SDH**]	
31	**Hemofil M**® [Hide in IT: **AHF**]	
32	**HEMORAAS** ®	
33	**Humate P** ®	
34	**Immunate** [Show in IT only: **Stim Plus**] ®	Hide in US & JP

35	[Hide in IT: **Koate DVI**] [IT only: **Koate HS**] ®	Hide in PT, AT, DE & CH & JP
36	**Monoclate P** ®	Hide in PT, AT, DE & CH & JP & IT
37	**Octanate**®	Hide in US & AT & JP
38	**Octanativ-M** ®	Hide in PT, US, DE & CH & JP & IT
39	**Optivate**®	Hide in CH, AT, DE & US & JP & IT
43	**Wilate**®	Hide in CH & JP
44	**Human Coagulation Factor VIII**	Hide in CH, DE & US & JP & IT
45	**Voncento** ®	DE only
97	[Hide in Germany: Other] Plasma-derived Factor VIII concentrate (please specify) **– MONITOR FOR AES**	Anchor, insert OE box

	Non-factor therapy	
50	**Hemlibra®**	Can be selected with another treatment, all others are single code unless specified
98	[Hide in Germany: Other] Non-Factor therapy (please specify) **– MONITOR FOR AES**	Anchor, insert OE box

	Bypassing agents	
60	**FEIBA** (Factor VIII Inhibitor Bypassing Activity)	
61	**NovoSeven® – NOVO NORDISK PRODUCT**	Can be selected with another treatment, all others are single code unless specified
62	**Byclot plasma-derived factor VIIa and FX**	JP only
99	[Hide in Germany: Other] bypassing agent (please specify) **– MONITOR FOR AES**	Anchor, insert OE box
100	**Other** (please specify)	Anchor, insert OE box
101	**None, current treatment is first treatment**	Show separate from list (i.e. one row below) exclusive code, anchor

Q33b. ASK IF Code 101 not selected @ Q33a

Single code per column

Which of the following best describes when [Patient: you] [Carer: the person you care for] used the following treatment(s)?

Please select one option for each treatment. 23

Columns

Insert treatments selected at Q33a, one per column

Rows – Randomise

1. Prophylactic treatment (regular treatment to prevent or reduce the number of bleeds) (Show for Hemlibra only)

2. Prophylactic treatment (regular treatment to prevent or reduce the number of bleeds). Additionally, extra doses may be given on-demand during a bleed

3. Only during a bleed as an 'on-demand' treatment

Q33c. ASK IF Code 101 not selected @ Q33a

Numeric

How long [Patient: were you] [Carer: was the person you care for] treated with the treatment(s) [Patient: you] [Carer: they] were receiving immediately prior to [Patient: your] [Carer: their] current treatment.

Columns

1. Years

2. Months

Rows

1. Current treatment: Pipe years and months from S9

2. Insert treatment(s) from Q33a (same row)

3. Show 'Total time on treatment' as running total

Range: Years 0-S5, Months 0-11

Total time treated (sum of S9 + Q33c) cannot be greater than time since diagnosis (S5)

Q34. ASK ALL - AE FLAG

Single code

Prior to starting [Patient: your] [Carer: their] current treatment, which of the following best describes the highest level of daily activities [Patient: you were] [Carer: the person you care for was] able to do.

Please select one option only. Your answer you selected for currently will be shown but cannot be edited.

Columns

a) Current activity status: Pipe answers from Q23, do not allow to edit

b) Prior to starting current treatment

Rows

1. Insert code options from Q23 (activity levels)

Q35. ASK ALL- AE FLAG

Numeric

Prior to starting [Patient: your] [Carer: their] current treatment, where did you perceive [Patient: your quality of life] [Carer: the quality of life of person you care for] was assuming an average person without hemophilia's quality of life is 100.

If you perceive that it was worse than an average person without hemophilia, please enter a number less than 100. If you perceive it was better, please enter a value over 100.

Your answer you entered for currently will be shown but cannot be edited.

Columns

a) Current quality of life: Pipe answer from Q26, do not allow to edit

b) Prior to starting current treatment

Rows

1. [_____]

Range 0-200

Q36. ASK ALL - AE FLAG

Single code per row

On a scale of 1-7, overall, how satisfied [Patient: were you] [Carer: was the person you care for] at each of the following times with the treatment approach.

Please answer on a scale from 1 to 7, where 1 is "Not at all satisfied" and 7 is "Completely Satisfied".

Columns

1. Not at all satisfied

2.

3.

4.

5.

6.

7. Completely satisfied

Rows- Randomise

1. Current treatment

2. Immediately prior to starting current treatment

Q36b. ASK IF Q33a = 101: – MONITOR FOR AES

Open end

Please describe why [Patient: you are] [Carer: you think the person you care for is] [insert # from Q36 row 1] out of 7 satisfied with [Patient: your] [Carer: their] **current treatment**?

Please provide as much detail as possible. In your answer, you can provide examples of the reason or a story explaining the experience since being prescribed the treatment.

Insert open end text box. Minimum 10 characters

Q37. ASK IF CODE 5, 6 OR 7 SELECTED @ Q36 ROW 1 25

Multicode and single select

Which of the following, if any, best describe why [Patient: you are] [Carer: you think the person you care for is] satisfied with [Patient: your] [Carer: their] current treatment?

Please select as many as apply and then the main reason.

Columns

a) Reasons for satisfaction – Multicode

b) Main reason – Single select

Rows (Most hope to achieve (Q31b) adapted) – Randomise in same order as Q31b

1. Higher trough levels to reduce the risk of bleeds

2. Lower number of bleeds per year (annualised bleeding rate)

3. Less frequent injections

4. Easy / quick treatment set-up

5. Increased storage flexibility of treatment

6. Less risk of adverse events

7. Able to use as an 'on-demand' treatment during a bleed

8. Less pain caused by hemophilia

9. Provides joint protection and improves joint health

10. Improved my quality of life

11. Reduced impact on daily living activities

12. Increased confidence in doing physical activity

13. Improved mental health and reduced stress and anxiety caused by Hemophilia

14. Other, please specify – Anchor, insert OE box **– MONITOR FOR AES**

Col B can only be selected from those in Col A

Q38a. ASK IF Q33a ≠ 101

1-5 scale

Which of the following describes [Patient: your treatment preference] [Carer: the treatment preference of the person you care for]?

Please select one option only.

1. Much prefer previous treatment

2. Prefer previous treatment

3. No preference

4. Prefer current treatment

5. Much prefer current treatment

Q38b. ASK IF Q33a ≠ 101 – MONITOR FOR AES

Open end

IF CODE 1 or 2 SELECTED @ Q38a: Please describe why [Patient: you prefer your] [Carer: you think the person you care for prefers their] **previous treatment**?

IF CODE 3 SELECTED @ Q38a: Please describe why [Patient: you do not] [Carer: you think the person you care for does not] **have a treatment preference**?

IF CODE 4 or 5 SELECTED @ Q38a: Please describe why [Patient: you prefer your] [Carer: you think the person you care for prefers their] **current treatment**?

Please provide as much detail as possible. In your answer, you can provide examples of the reason or a story explaining the experience.

Insert open end text box. Minimum 10 characters.

Q39. ASK ALL

Single select, 1-5 scale – AE FLAG FOR CURRENT TREATMENT, ESPEROCT (NN PRODUCT) AND COL 1 OR 2 SELECTED FOR STATEMENTS 7 OR 8

On a scale of 1-5, how much do you [Carer: think the person you care for would] **agree** with each of the following statements below about [Patient: your] [Carer: their] current treatment?

[Patient: My current treatment…] [Carer: The current treatment of the person I care for…]

Please use a scale of 1 to 5 where 1 is "I strongly disagree" and 5 is "I strongly agree"

Columns

1. Strongly disagree

2. Disagree

3. Neither agree nor disagree

4. Agree

5. Strongly agree

Statements - Randomize

1. Has had a positive impact on overall quality of daily life

2. Has had a positive impact on activities of daily living

3. Helped [patient: me] [Carer: him/her] to feel more confident than before in ability to undertake physical activities

4. Has allowed for [patient: me] [Carer: him/her] to undertake more / different activities

5. Has reduced the levels of pain experienced due to hemophilia

6. Is convenient to take

7. Offers better joint protection and more stable joint health

8. Reduces / prevents bleeds (annualized bleeding rate)

Q40. ASK ALL

Multicode

Which of the following, if any, have [Patient: you] [Carer: the person you care for] experienced since [Patient: you] [Carer: they] started taking [Patient: your] [Carer: their] current treatment?
Please select as many as apply.

1. Insert list from Q32b (convenience list) in randomized order

Q41. ASK ALL

Single code per row

We now would like to understand a little more about how [Patient: your] [Carer: their] current treatment has affected [Patient: your life] [Carer: the life of the person you care for]. On a scale of 1-5, how would you rate the impact on each statement below?
Please answer on a scale from 1 to 5, where 1 is "Significant negative impact" and 5 is "Significant positive impact".

Columns

1. Significant negative impact

2. Some negative impact

3. No positive impact vs. prior to current treatment

4. Some positive impact

5. Significant positive impact

Statements

1. Insert list from Q22 (Impact on life / activities list)

Q42a. ASK IF PATIENT & COL 4-5 SELECTED @ Q41 FOR CODE 5 'Education / work'

Multi code – Randomize in bracket

Which of the following best describes the positive impact your current treatment has had on

your **education and/or ability to work**?

Please select as many as apply.

Work bracket – if code 1-3 selected at Q24

1. Fewer days missed

2. Able to work an increased number of hours

3. Able to accept a promotion or pursue a career

4. Able to work in a more demanding role (e.g., manage a team, required to travel,

unpredictable hours / responsibilities)

5. Able to work in a more satisfying role

Education bracket – if code 8-9 selected at Q24

6. Able to return to education

7. Less days of school / college missed

8. Able to complete educational qualification (e.g., GCSEs)

9. Able to participate more in physical education classes / after school or college sports clubs

10. Able to go on school / college trips

11. Able to have a job whilst studying – Show if code 1-3 selected at Q24 additionally

12. Reduced concerns about ability to work full-time in the future

13. Reduced concerns about ability to work in a demanding role (e.g., manage a team, required to travel, unpredictable hours / responsibilities)

14. Reduced concerns about ability to work in a satisfying role

Other

15. Able to attend events / socialize with friends [if code 1-3 @ Q24 / colleagues]

16. Other (please specify) – Insert OE box – anchor - MONITOR FOR AES

Q42b. ASK IF CARER & COL 4-5 SELECTED @ Q41 FOR CODE 5 'Education / work'

Multi code

Which of the following best describes the positive impact the current treatment of the person you care for has had on their **education and/or ability to work**?

Please select as many as apply.

1. Less days of school missed

2. Able to complete educational qualification (e.g., GCSEs, A-levels)

3. Able to participate more in physical education classes / after school or college sports clubs

4. Able to go on school trips / college trips

5. Able to have a part time job

6. Reduced concerns about ability to work full-time in the future

7. Reduced concerns about ability to work in a demanding role (e.g., manage a team, required to travel, unpredictable hours / responsibilities)

8. Reduced concerns about ability to work in a satisfying role

9. Able to attend events / socialize with friends

10. Other (please specify) – Insert OE box – anchor – MONITOR FOR AES

Q42c. ASK IF COL 4-5 SELECTED @ Q41 FOR CODE 7 'ability to go on holiday / travel'

Multi code 28

Which of the following best describes the positive impact [Patient: your current treatment] [Carer: the current treatment of the person you care for] has had on [Patient: your] [Carer: their] **ability to go on holiday / travel**?

Please select as many as apply.

1. Less planning in advance required

2. Easier to carry treatment and equipment

3. Easier storage of treatment and / or less concerns about storage (e.g. amount of fridge space)

4. Reduced fear of having a bleed whilst away from home

5. Able to travel further away from home

6. Treatment required less frequently

7. Able to travel more often

8. Other (please specify) - MONITOR FOR AES

Q42d. ASK IF PATIENT & COL 1-2 SELECTED @ Q41 FOR CODE 5 'Education / work'

Multi code – Randomize in bracket

Which of the following best describes the negative impact your current treatment has had on **your education and/or ability to work**?

Please select as many as apply.

Work bracket if code 1-3 selected @ Q24

1. More days missed

2. Had to reduce number of hours worked

3. Rejected a promotion or did not seek a career

4. Moved to a less demanding role (e.g., no team to manage, no travel required, predictable hours / responsibilities)

5. Moved to a less satisfying role

6. Unable to return to education

Education bracket if code 8-9 select @ Q24

7. More days of school / college missed

8. Unable to complete educational qualification (e.g., GCSEs)

9. Unable to participate in physical education classes / after school or college sports clubs

10. Unable to go on school / college trips

11. Unable to have a part-time job whilst studying - Only show if code 1-3 NOT selected at Q24

12. More concerns about ability to work full-time in the future

13. More concerns about ability to work in a demanding role (e.g., manage a team, required to travel, unpredictable hours / responsibilities)

14. More concerns about ability to work in a satisfying role

Other

15. Unable to attend events / socialize with friends [if code 1-3 @ Q24 / colleagues]

16. Other (please specify) – Insert OE box – anchor - MONITOR FOR AES

Q42e. ASK IF CARER & COL 1-2 SELECTED @ Q41 FOR CODE 5 'Education / work'

Multi code

Which of the following best describes the negative impact the current treatment of the person you care for has had on their **education and/or ability to work**?

Please select as many as apply.

1. More days of school missed

2. Unable to complete educational qualification (e.g., GCSEs, A-levels)

3. Unable to participate in physical education classes / after school or college sports clubs

4. Unable to go on school / college trips

5. Unable to have a part-time job

6. More concerns about ability to work full-time in the future

7. More concerns about ability to work in a demanding role (e.g., manage a team, required to travel, unpredictable hours / responsibilities)

8. More concerns about ability to work in a satisfying role

9. Unable to attend events / socialize with friends

10. Other (please specify) – Insert OE box – anchor- MONITOR FOR AES

Q42f. ASK IF COL 1-2 SELECTED @ Q41 FOR CODE 7 'ability to go on holiday / travel'

Multi code

Which of the following best describes the negative impact [Patient: your current treatment] [Carer: the current treatment of the person you care for] has had on [Patient: your] [Carer: their] **ability to go on holiday / travel**?

Please select as many as apply.

1. More planning in advance required

2. More difficult to carry treatment and equipment

3. More difficult storage of treatment and / or more concerns about storage (e.g., amount of fridge space)

4. Increased fear of having a bleed whilst away from home

5. Unable to travel far away from home

6. Treatment required more frequently

7. Unable to travel frequently

8. Other (please specify) – Insert OE box – anchor - MONITOR FOR AES

Q43. ASK ALL (MONITOR FOR AES)

Single code per row

To what extent do you think [Patient: your current treatment] [Carer: the current treatment of the person you care for] is better, the same or worse on each of the following areas.

[Q33a ≠ 101: *Please select your answer on the scale where 1 is "Significantly worse than previous treatment" and 5 is "Significantly better than previous treatment".*]

[Q33a = 101: *Please select your answer on the scale where 1 is "Significantly worse than prior to starting treatment" and 5 is "Significantly better prior to starting treatment".*]

Columns - Q33a ≠ 101

1. Significantly worse than previous treatment **– AE FLAG (ESPEROCT)**

2. Worse than previous treatment **– AE FLAG (ESPEROCT)**

3. About the same as previous treatment

4. Better than previous treatment **– AE FLAG (NN PRODUCT PREVIOUSLY @ Q33a)**

5. Significantly better than previous treatment **– AE FLAG (NN PRODUCT PREVIOUSLY @ Q33a)**

Columns - Q33a = 101

1. Significantly worse than prior to starting current treatment **– AE FLAG (ESPEROCT)**

2. Worse than prior to starting current treatment **– AE FLAG (ESPEROCT)**

3. About the same as prior to starting current treatment

4. Better than prior to starting current treatment **– AE FLAG (NN PRODUCT PREVIOUSLY @ Q33a)**

5. Significantly better than prior to starting current treatment **– AE FLAG (NN PRODUCT PREVIOUSLY @ Q33a)**

Statements – Adapted from Q31b (hopes) – Randomise in same order as Q31b

1. Trough levels (to reduce the risk of bleeds) **– AE FLAG**

2. Number of bleeds per year (annualised bleeding rate) **– AE FLAG**

3. Frequency of injections

4. Easy / quick treatment set-up

5. Storage flexibility of treatment

6. Adverse events **– AE FLAG**

7. Ability to use as an 'on-demand' treatment during a bleed

8. Pain caused by hemophilia **– AE FLAG**

9. Joint protection and joint health **– AE FLAG**

10. Quality of life

11. Impact on daily living activities

12. Confidence in doing physical activity

13. Mental health, stress and anxiety caused by Hemophilia

99. Pipe from code 99 @ Q31b if 'other' selected

Q44. ASK ALL (MONITOR FOR AES)

Single code per row

Again, to what extent do you think [Patient: your current treatment] [Carer: the current treatment of the person you care for] is better, the same or worse on each of the following feelings.

[Q33a ≠ 101: *Please select your answer on the scale where 1 is "Significantly worse than previous treatment" and 5 is "Significantly better than previous treatment".*]

[Q33a = 101: *Please select your answer on the scale where 1 is "Significantly worse than prior to starting treatment" and 5 is "Significantly better prior to starting treatment".*]

Columns – Q33a ≠ 101

1. Significantly worse than previous treatment

2. Worse than previous treatment

3. About the same as previous treatment

4. Better than previous treatment

5. Significantly better than previous treatment

Columns - Q33a = 101

1. Significantly worse than prior to starting current treatment

2. Worse than prior to starting current treatment

3. About the same as prior to starting current treatment

4. Better than prior to starting current treatment

5. Significantly better than prior to starting current treatment

Rows – Randomize

1. Feeling of being free / unbound

2. Feeling of optimism / hope

3. Feeling of being in control of hemophilia

4. Ability to think less about hemophilia

Section 4: Demographics & closing questions (~2 min)

D1. ASK ALL

Single code - Randomise

Which of the following best describes [patient: your gender] [carer: the gender of the person you care for]?

Please select one option only.

1. Male

2. Female

3. Non-binary HIDE IN JP

4. Prefer not to say - Anchor

D2. ASK ALL

Single code

In which region [patient: do you] [carer: does the person you care for] live?

Please select one option only.

Austria:

1. Burgenland

2. Kaernten

3. Niederoesterreich

4. Oberoesterreich

5. Salzburg

6. Steiermark

7. Tirol

8. Vorarlberg

9. Wien

Germany:

1. Baden-Württemberg

2. Bayern

3. Berlin

4. Brandenburg

5. Bremen

6. Hamburg

7. Hessen

8. Mecklenburg-Vorpommern

9. Niedersachsen

10. Nordrhein-Westfalen

11. Rheinland-Pfalz

12. Saarland

13. Sachsen

14. Sachsen-Anhalt

15. Schleswig-Holstein

16. Thüringen

Italy:

1. Abruzzo

2. Basilicata

3. Calabria

4. Campania

5. Emilia-Romagna

6. Friuli-Venezia Giulia

7. Lazio

8. Liguria

9. Lombardia

10. Marche

11. Molise

12. Piemonte

13. Puglia

14. Sardegna

15. Sicilia

16. Toscana

17. Trentino-Alto Adige

18. Umbria

19. Valle d'Aosta

20. Veneto

Japan:

1. Hokkaido

2. Tohoku

3. Kanto

4. Chubu

5. Kinki

6. Chugoku (added)

7. Shikoku

8. Kyusyu-Okinawa

Portugal:

1. Alentejo

2. Algarve

3. Acores

4. Centro

5. Lisboa

6. Madeira

7. Norte

Spain:

1. Andalucía

2. Aragón

3. Asturias (Principado de)

4. Balears (Illes)

5. Canarias

6. Cantabria

7. Castilla - La Mancha

8. Castilla y León

9. Cataluña

10. Ceuta and Melilla

11. Comunidad Valenciana

12. Extremadura

13. Galicia

14. Madrid (Com. De)

15. Murcia (Región de)

16. Navarra (C. Foral de)

17. País Vasco

18. Rioja (La)

Switzerland:

1. Aargau

2. Appenzell Ausserrhoden

3. Appenzell Innerrhoden

4. Basel-Landschaft

5. Basel-Stadt

6. Bern

7. Fribourg

8. Genève

9. Glarus

10. Graubünden

11. Jura

12. Luzern

13. Neuchâtel

14. Nidwalden

15. Obwalden

16. Sankt Gallen

17. Schaffhausen

18. Schwyz

19. Solothurn

20. Thurgau

21. Ticino

22. Uri

23. Vaud

24. Wallis

25. Zug

26. Zürich

UK:

1. East Anglia

2. East Midlands

3. London

4. North East

5. North West

6. Northern Ireland

7. Scotland

8. South East

9. South West

10. Wales

11. West Midlands

12. Yorkshire & Humberside

USA:

1. Alabama

2. Alaska

3. Arizona

4. Arkansas

5. California

6. Colorado

7. Connecticut

8. Delaware

9. District of Columbia

10. Florida

11. Georgia

12. Hawaii

13. Idaho

14. Illinois

15. Indiana

16. Iowa

17. Kansas

18. Kentucky

19. Louisiana

20. Maine

21. Maryland

22. Massachusetts

23. Michigan

24. Minnesota

25. Mississippi

26. Missouri

27. Montana

28. Nebraska

29. Nevada

30. New Hampshire

31. New Jersey

32. New Mexico

33. New York

34. North Carolina

35. North Dakota

36. Ohio

37. Oklahoma

38. Oregon

39. Pennsylvania

40. Rhode Island

41. South Carolina

42. South Dakota

43. Tennessee

44. Texas

45. Utah

46. Vermont

47. Virginia

48. Washington

49. West Virginia

50. Wisconsin

51. Wyoming

Single code

Which of the following best describes your household?

Please select one option only.

1. Live alone and independently

2. Live independently with partner or relatives / friends

3. Live alone but am dependant on someone who visits to support me, either professionally or

unprofessionally

4. Live with partner or relatives / friends who I am dependent on for support

5. Other, please specify (Insert OE box) **– MONITOR FOR AES**

6. Prefer not to say

Qintro4.2. SHOW CARERS ONLY

Text

Finally, we would like to ask you a few questions about **yourself**.

C1. SHOW CARERS ONLY 35

Single code - Randomise

Which of the following best describes **your** gender?

Please select one option only.

1. Male

2. Female

3. Non-binary HIDE IN JP

4. Prefer not to say - Anchor

C2. SHOW CARERS ONLY

Single code

What is **your** current employment status?

Please select one option only.

1. Insert list from Q24 (employment status) in same order

Cannot select code 1-5 together, Cannot select code 8-9 together, Cannot select code 1,

7 and 9 together

Q CLOSE1. ASK ALL

Single code

Would you be willing to be re-contacted in the future, if we have any clarifications or further questions?

Please select one option only.

1. Yes

2. No

Q CLOSE2. ASK ALL BUT DO NOT FORCE ANSWER

OPEN END - MONITOR FOR AEs

Thank you for participating in this study. Your contribution is greatly appreciated.

Do you have any feedback on this survey? This could for example be regarding the layout and structure of the survey, the types of questions we asked or how engaging you found the survey.

Please do not include any reference to treatments in your feedback.

INSERT OPEN END TEXT BOX