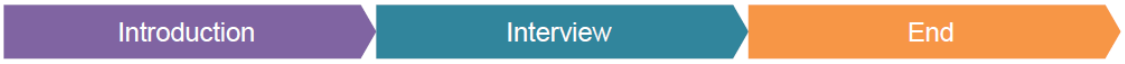
Supplementary file2

1， Objective of this survey

- The objective of this survey is to explore how patients with PNH (subjects) perceive their health, daily life, and emotions, which are affected by their symptoms and treatment.
- This interview guide is used to facilitate the necessary interviews to achieve the objective of this survey, but it is not necessary to be worded exactly as described here.
- The explanations by an interviewer to a subject is written in blue letters, questions to the subject are in red letters, and explanations intended to enhance the interviewers' understanding are in black letters (supplementary explanations are in gray letters).
- Depending on the subject's response, follow-up probes (further questions to deepen the discussion) are shown in orange letters.
- To conduct the interview, please check the following points.
  - ➢ In case a subject's response or more detailed information is additionally needed, other questions or follow-up probes may be added.
  - ➢ Questions about information that the subject has already answered should not be repeated (as far as possible).
  - ➢ All interviews will take approximately 60 minutes.
  - ➢ Please try to arrange the conversation and finish the interview within the allocated time.

2， Interview Flow

- The flow of the interview is as follows:



- The objectives of each interview item are shown in the table below:

Item	Objective
First Interview Item	• To build a trusting relationship and make the subject feel comfortable so that they can speak spontaneously • Get the subject to spontaneously discuss experiences with health issues
Second Interview Item	• To identify issues involving PNH symptoms or adverse drug reactions to PNH treatment that the subject does not present spontaneously
Third Interview Item	• To identify issues concerning the burden of PNH treatment that the subject does not present spontaneously
Fourth Interview Item	• To show how health issues affect the daily life of the subject
Fifth Interview Item	• To determine how health issues affect the subject's emotions due to effects on the subject's daily life

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Sixth Interview Item	• To identify the issue that the subject considers the most undesirable and the reason
Seventh Interview Item	• To show how health issues may affect the subject • This is a supplementary interview item. If sufficient answers have been obtained for the previous interview items, this item will not be included in the interview
Eighth Interview Item	• To clarify desirable and undesirable treatment for the subject

- Materials used by the subject and the interviewer at each interview are as shown in the table below:

Item	Subject	Interviewer
Introduction	• None	• None
First Interview Item	• None	• [For the Interviewer (1) Today's Health Condition] • [For the Interviewer (2) Symptoms of PNH] • [For the Interviewer (3) Adverse Drug Reactions due to PNH Treatment] • [For the Interviewer (4) Burden of PNH Treatment]
Second Interview Item	• [For the Subject (1) Symptoms of PNH] • [For the Subject (2) Adverse Drug Reactions due to PNH Treatment]	• [For the Interviewer (2) Symptoms of PNH] • [For the Interviewer (3) Adverse Drug Reactions due to PNH Treatment]
Third Interview Item	• [For the Subject (3) Burden of PNH Treatment]	• [For the Interviewer (4) Burden of PNH Treatment]
Fourth Interview Item	• [For the Subject (4) Areas of Daily Life]	• [For the Interviewer (5) Areas of Daily Life]
Fifth Interview Item	• [For the Subject (5) Areas of Emotions]	• [For the Interviewer (6) Areas of Emotions]
Sixth Interview Item	• None	• None
Seventh Interview Item	• [For the Subject (4) Areas of Daily Life] • [For the Subject (5) Areas of Emotions]	• None

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Eighth Interview Item	• [For the Subject (6) Desirable and Undesirable Treatments] • [For the Subject (7) Areas of Daily Life] • [For the Subject (8) Areas of Emotions]	• [For the Interviewer (7) Desirable and Undesirable Treatments] • [For the Interviewer (8) Areas of Daily Life] • [For the Interviewer (9) Areas of Emotions]
End	• None	• None

3， Interview Gide

（1） Introduction

Estimated time	Interviewer
3 minutes 3/60	(Good morning/Good afternoon/Good evening). Thank you for your cooperation with this survey. I am <the interviewer's name>. The objective of this survey is to talk to some other people who are participating in this survey like you and to ask how they feel about PNH symptoms and treatment, and to obtain a deeper understanding of how the health issues they have experienced so far have affected their daily lives and emotions. Again, thank you very much for taking the time to participate in this survey today. The interview will last approximately 60 minutes. To grasp what you say as accurately as possible, I would like to record this interview in addition to having everything written down by the secretary. Please answer the questions honestly and feel free to discuss your opinions or experiences that you had. There are no right or wrong answers. Participation in this survey is entirely at your free will. You may decline to answer questions that you do not want to discuss. You may also stop participating in this interview at any time without any penalty. Your privacy will be protected. Your name and other personal information that can identify you will not be used. During the interview, please refrain from making comments that can identify individuals as far as possible. When using the interview results collected from the subjects, you will be identified by the number allocated to you to maintain confidentiality.
	Question A: You have already agreed to participate in the survey and this interview. As stated in the consent form, may I make a recording of today's interview to use for the records?
	➢ If the answer to Question A is "Yes"

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	When the secretary has started recording, read the date of the interview and verify the identity of the subject by reading the person's ID number. Then check if the subject has any questions. Question B: Before starting the interview, is there anything you do not understand? Answer any questions of the subject as appropriate. If there is a question that you cannot answer, please ask the Clinical Experience Investigation Manager.
	➢ If the answer to Question A is "No" If the subject answers "No" or shows some confusion when consent for recording the interview is confirmed, please explain the contents described in the consent form again. As described in the consent form, your name will not be recorded or written out, and will not be linked to your answers in the interview. If the answer to Question A is "No" even after an additional explanation. Unfortunately, you cannot participate in this survey if you do not allow recording of this interview. Thank you for your time.

（2）First Interview Item

Estimated time	Interviewer
1 minute 4/60	Before getting to the main topic, make the subject feel comfortable so that subsequent questions can be answered spontaneously. First, tell me a little bit about yourself. Please relax and talk. Question 1-1: Where did you come from to participate in this study today? If the subject seems to be at a lost for an answer, please give specific examples in reference to the living room or his/her own room. If the subject still looks nervous after Question 1-1, talk about the weather like, "It has cooled down suddenly in the past few days. Isn't your room cold?" or "It's gradually getting hotter."
1 minute 5/60	Question 1-2: If the best health condition you can imagine is 100 points and the worst health condition is 0 points, how would you rate your health condition today? Please show [For the Interviewer (1) Today's Health Condition] to the subject and ask him/her to respond. Mark an X on the scale of [For the Interviewer (1) Today's Health Condition] and write down the points that the subject mentioned.

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4 minutes 9/60	You will be asked questions about your general health condition and illnesses. Health does not only concern illnesses but also physical and mental health, social health (such as the ability to build a positive and good relationship with others and society), as well as interpersonal relationships. Question 1-3: Please talk about your current health condition and illnesses in general. How would you describe your current health condition? Please feel free to talk about anything, both good and bad points. If there are any comments on the items of [For the Interviewer (2) Symptoms of PNH Treatment], [For the Interviewer (3) Adverse Drug Reactions due to PNH Treatment], and [For the Interviewer (4) Burden of PNH Treatment] among the responses of the subject, please mark a circle in the column of "Spontaneously Expressed."
	Thank you for your reply. Please tell me more about what you said. Question 1-4: Are the general health condition and illness you answered earlier (Question 1-3) caused by "PNH symptoms and treatment"? If you are not sure, please say so. Supplementary information: PNH(Paroxysmal nocturnal hemoglobinuria): A hematologic disease, which attributed to a genetic mutation and is characterized by symptoms of anemia (such as light-headedness, breathlessness and palpitations) as well as black urine in the early morning. If the subject forgets the previous answer, let the person answer the items marked with a circle in [For the Interviewer (2) Symptoms of PNH], [For the Interviewer (3) Adverse Drug Reactions due to PNH Treatment], and [For the Interviewer (4) Burden of PNH Treatment].
2 minutes 11/60	Next, Please tell me about your PNH treatment. Question 1-5: Please tell me how you feel about your PNH treatment? Please feel free to talk about anything regarding your current treatment, both good and bad points. If there are any comments on the items of [For the Interviewer (4) Burden of PNH Treatment] among the responses of the subject, please mark a circle in the column of "Spontaneously Expressed."

[For the Interviewer (1) Today's Health Condition]

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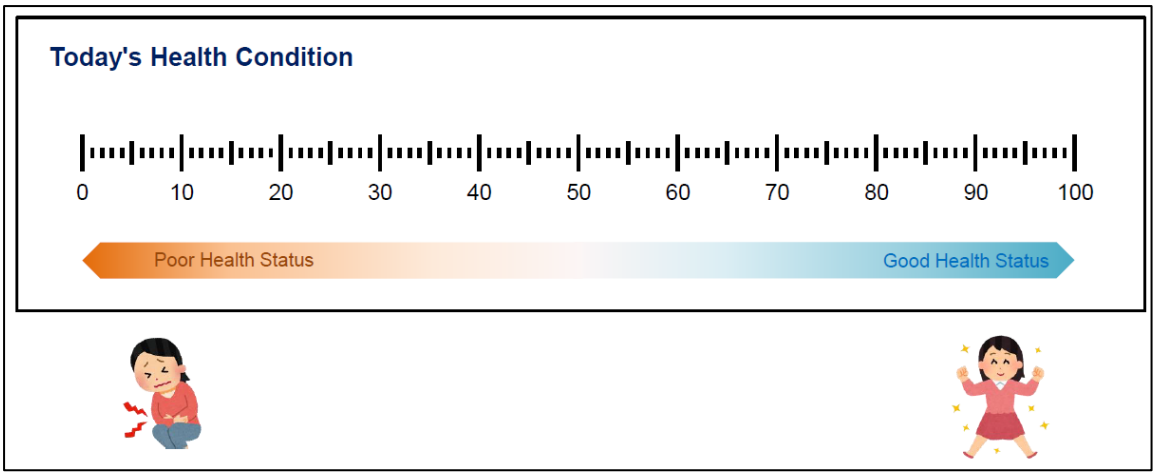

[For the Interviewer (2) Symptoms of PNH]

Number	Spontaneously Expressed	Responded to Follow-Up Probes	Item
1			Feel pain in stomach (leg, chest, back, or low back)
2			Feel difficulty breathing when performing some exercise (walking)
3			Blackish urine
4			Feel tired easily compared to before
5			Sometimes unable to concentrate on tasks (including work and study)
6			Feel tired even after sleeping
7			Feel difficulty on swallowing food, feel pain when swallowed
8			Appetite decreased
9			Blood pressure increased
10			Yellowish skin
11			No erection despite excitation (*only men)
12			Complications (renal failure, thrombosis, MDS*/leukemia) developed

*MDS: Myelodysplastic syndromes

[For the Interviewer (3) Adverse Drug Reactions due to PNH Treatment]

Number	Spontaneously Expressed	Responded to Follow-Up Probes	Item
1			The face became round and acne developed

2			Broke a bone despite hitting it only slightly
3			Became susceptible to colds
4			Felt pain in the stomach or the frequency of bowel movements decreased
5			Felt pain in the head, throat, or muscles, etc.
6			Develop nausea and feeling nauseous
7			Experience skin reddening or itching

[For the Interviewer (4) Burden of PNH Treatment]

Number	Spontaneously Expressed	Responded to Follow-Up Probes	Item
1			Often have to miss work due to hospital visits
2			Often have to miss school due to hospital visits
3			Hospitals with specialized outpatient clinics are far away or there are no hospitals
4			Sometimes forget to take the medicine
5			Feel that the amount of copayment for treatment (including expenses for hospital visits) is high
6			Feel uneasy about having to continue treatment for the rest of life
7			Long waiting time at hospital
8			Long hospital stay for treatment
9			Unable to go on a long-term trip due to regular treatment
10			Unable to go on a long-term business trip due to regular treatment
11			It is difficult to insert a needle properly into a blood vessel
12			Unable to continue diet therapy
13			Unable to continue exercise therapy

（3）Second Interview Item

Estimated time	Interviewer

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2 minutes 13/60	Please explain [For the Subject (1) Symptoms of PNH] and [For the Subject (2) Adverse Drug Reactions due to PNH Treatment] to the subject by presenting examples to the subject. Supplementary information: There are similar expressions in each item of [For the Subject (1) Symptoms of PNH] and [For the Subject (2) Adverse Drug Reactions due to PNH Treatment]. However, the images that the subjects have of the expressions differ depending on the subject; therefore, please check by showing similar expressions. Question 2-1: Symptoms and Adverse Drug Reactions due to PNH listed by other people are described in [For the Subject (1) Symptoms of PNH] and [For the Subject (2) Adverse Drug Reactions due to PNH Treatment]. Have you experienced these symptoms? If you have experienced any symptoms, please tell me the number. For items answered by the subject, please mark a circle in the column of "Responded to Follow-Up Probes" in [For the Interviewer (2) Symptoms of PNH] and [For the Interviewer (3) Adverse Drug Reactions due to PNH Treatment]. If the subject asks questions about the recall period, don't ask about things that happened long ago, but ask about recent experiences. Also, if you are asked how long "recent" is, tell the subject, "the last few weeks."
6 minutes 18/60	In [For the Interviewer (2) Symptoms of PNH] and [For the Interviewer (3) Adverse Drug Reactions due to PNH Treatment], ask questions about each item that are not marked with a circle in either "Spontaneously Expressed" or "Responded to Follow-Up Probes."
	Question 2-2: Do you mean that you have not experienced anything in particular about XX (to be read out for items not marked with a circle in [For the Subject (1) Symptoms of PNH] and [For the Subject (2) Adverse Drug Reactions due to PNH Treatment])? In the same way, please ask the subject about items in [For the Subject (1) Symptoms of PNH] and [For the Subject (2) Adverse Drug Reactions due to PNH Treatment].
- minutes -/60	If it has taken a long time until here, skip Question 2-3.
	Question 2-3: Please let me know if you have experienced any "health issues" other than the items you have answered so far. Please also tell me about how they affect your daily life.

[For the Subject (1) Symptoms of PNH]

Number	Item

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1	Feel pain in stomach (leg, chest, back, or low back)
2	Feel difficulty breathing when performing some exercise (walking)
3	Blackish urine
4	Feel tired easily compared to before
5	Sometimes unable to concentrate on tasks (including work and study)
6	Feel tired even after sleeping
7	Feel difficulty on swallowing food, feel pain when swallowed
8	Appetite decreased
9	Blood pressure increased
10	Yellowish skin
11	No erection despite excitation (*only men)
12	Complications (renal failure, thrombosis, MDS*/leukemia) developed

*MDS: Myelodysplastic syndromes

[For the Interviewer (2) Adverse Drug Reactions due to PNH Treatment]

Number	Item
1	The face became round and acne developed
2	Broke a bone despite hitting it only slightly
3	Became susceptible to colds
4	Felt pain in the stomach or the frequency of bowel movements decreased
5	Felt pain in the head, throat, or muscles, etc.
6	Develop nausea and feeling nauseous
7	Experience skin reddening or itching

（4） Third Interview Item

Estimated time	Interviewer
1 minute 19/60	Please explain [For the Subject (3) Burden of PNH Treatment] to the subject by presenting examples. Supplementary information: There are similar expressions in each item of [For the Subject (3) Burden of PNH Treatment]. However,the images that the subjects have of the expressions differ depending on the subject; therefore, please check by showing similar expressions. Question 3-1: The list of the burden of PNH Treatment chosen by other people is described in [For the Subject (3) Burden of PNH Treatment]. Have you experienced any such burden? If you have experienced any burden, please provide the number.

	For items answered by the subject, please mark a circle in the column of "Responded to Follow-Up Probes" in [For the Interviewer (4) Burden of PNH Treatment]. If the subject asks questions about the recall period, don't ask about things that happened long ago, but ask about recent experiences. Also, if you are asked how long "recent" is, tell the subject, "the last few weeks."
3 minutes 22/60	In [For the Subject (3) Burden of PNH Treatment], ask questions about each item that are not marked with a circle in either "Spontaneously Expressed" or "Responded to Follow-Up Probes."
	Question 3-2: Do you mean that you have not experienced anything in particular about XX (to be read out for items not marked with a circle in [For the Subject (3) Burden of PNH Treatment]? In the same way, please ask the subject about items in [For the Subject (3) Burden of PNH Treatment].
- minutes -/60	If it has taken a long time until here, skip Question 3-3.
	Question 3-3: Please tell me about any other "health issues" than the ones you have mentioned so far that you experienced. Please also tell me about how they affect your daily life.

[For the Subject (3) Burden of PNH Treatment]

Number	Item
1	Often have to miss work due to hospital visits
2	Often have to miss school due to hospital visits
3	Hospitals with specialized outpatient clinics are far away or there are no hospitals
4	Sometimes forget to take the medicine
5	Feel that the amount of copayment for treatment (including expenses for hospital visits) is high
6	Feel uneasy about having to continue treatment for the rest of life
7	Long waiting time at hospital
8	Long hospital stay for treatment
9	Unable to go on a long-term trip due to regular treatment
10	Unable to go on a long-term business trip due to regular treatment
11	It is difficult to insert a needle properly into a blood vessel
12	Unable to continue diet therapy
13	Unable to continue exercise therapy

（5）Fourth Interview Item

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Estimated time	Interviewer
3 minutes 25/60	For the second and third interview items, subjects are asked about health-related items that they have experienced. In the fourth interview item, subjects are asked more specifically about the effects they experienced in their daily lives. The effects on emotions will be captured in the fifth interview item.
	Question 4-1: What aspects of your daily life have been affected by each of the "health issues" you have experienced? If it is a burden for you to reply, you do not have to force yourself to answer. If the subject can't think of specific situations “where they felt an effect," please explain that the subject’s daily life, work, study, and relationship with other people around them are included. If there are any comments on the items of [For the Interviewer (5) Areas of Daily Life] among the responses of the subject, please mark a circle in the column of "Spontaneously Expressed." If there are no categories, please fill in the content in the free text box below.
6 minutes 31/60	Please ask about the areas of daily life that are not mentioned by the subject in Question 4-1. Please explain [For the Subject (6) Areas of Daily Life] to the subject by presenting examples. According to your earlier reply, your "health issues" have effects on XX and XX (areas of daily life marked with a circle in the column of "Spontaneously Expressed” in [For the Interviewer (5) Areas of Daily Life]). Concerning the range of effects of “health issues,” other people have noted the following items besides the ones you mentioned.
	Please ask the subject about the areas of daily life that are not marked with a circle for "Spontaneously Expressed" in Question 4.1. Question 4-2: Didn’t your health issues have any particular effect on "1. Movement (walking, running)"? If any, what kind of effect did they have? If it is a burden for you to reply, you do not have to force yourself to answer. For any comments by the subject, please mark a circle in the column of "Responded to Follow-Up Probes."
	Please repeat the same for other areas of daily life until "11. Overall Quality of Life".

[For the Interviewer (5) Areas of Daily Life]

Number	Spontaneously Expressed	Responded to Follow-Up Probes	Item
1			Movement (walking, running)

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2			Cleverness (using the fingers or fingertips)
3			Daily life inside the house, such as housework
4			Daily life outside the house such as going out
5			Work and study
6			Relationships with family, friends and relatives
7			Relationships with colleagues and others at work, and other people
8			Independence (not being a burden to others, including family, friends, and people who are not close)
9			Daily self-management of physical condition
10			Unable to do what I wanted to do due to treatment
11			Overall quality of life
[Free text box]			

[For the Subject (4) Areas of Daily Life]

Number	Item
1	Movement (walking, running)
2	Cleverness (using the fingers or fingertips)
3	Daily life inside the house, such as housework
4	Daily life outside the house such as going out
5	Work and study
6	Relationships with family, friends and relatives
7	Relationships with colleagues and others at work, and other people
8	Independence (not being a burden to others, including family, friends, and people who are not close)
9	Daily self-management of physical condition
10	Unable to do what I wanted to do due to treatment
11	Overall quality of life

（6） Fifth Interview Item

Estimated time	Interviewer
3 minutes 34/60	For the fourth interview item, subjects are asked how the health-related items they have experienced affect their daily life. With this interview item, subjects are asked how the effects on their daily life affect their emotions and feelings.
	Question 5-1: How did the "health issues" or “effects on daily life” you have experienced affect your emotions and feelings? Which "health issues" or "effects on daily life" have affected them? If the subject can't think of specific examples as "effects on the emotions and feelings," please explain that these include feelings such as anxiety, sadness, and distress. If there are any comments on the items of [For the Interviewer (6) Areas of Emotions] among the responses of the subject, please mark a circle in the column of "Spontaneously Expressed." If there are no categories, please fill in the content in the free text box below.
6 minutes 40/60	Please ask about the areas of daily life that are not mentioned by the subject in Question 5-1. Please explain [For the Subject (7) Areas of Emotions] to the subject by presenting examples. According to your earlier reply, your "health issues" and “effects on daily life” have an effect on XX and XX (areas of emotions marked with a circle in the column of "Spontaneously Expressed” in [For the Interviewer (6) Areas of Emotions]). Concerning the range of effects of "health issues" and “effects on daily life,” other people have noted the following items besides the ones you mentioned.
	Please ask the subject about areas of emotions that are not marked with a circle for "Spontaneously Expressed" in Question 5.1. Question 5-2: Didn’t your health issues and the effects on your daily life have a particular effect on "1. Becoming anxious or feeling scared”? If any, what kind of effect did they have? If it is a burden for you to reply, you do not have to force yourself to answer. For any comments by the subject, please mark a circle in the column of "Responded to Follow-Up Probes."
	Please repeat the same for other areas of emotions up to "11. Feelings about the high medical costs borne by the local and central governments."

[For the Interviewer (6) Areas of Emotions]

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Number	Spontaneously Expressed	Responded to Follow-Up Probes	Item
1			Become anxious or scared
2			Become sad or pessimistic
3			Feeling disgusted or uncomfortable with myself (self-denial)
4			Feeling frustrated and angry with myself or others
5			Feeling distressed and suffering
6			Think it would be good to maintain the present situation
7			Feel dissatisfied
8			Feel shame (embarrassed, ashamed)
9			Become disgusted with life-long treatment
10			Feel sorry for putting a burden on others
11			Feeling about the high medical costs borne by the local and central governments
[Free text box]			

[For the Subject (5) Areas of Emotions]

Number	Item
1	Become anxious or scared
2	Become sad or pessimistic
3	Feeling disgusted or uncomfortable with myself (self-denial)
4	Feeling frustrated and angry with myself or others
5	Feeling distressed and suffering
6	Think it would be good to maintain the present situation
7	Feel dissatisfied
8	Feel shame (embarrassed, ashamed)
9	Become disgusted with life-long treatment
10	Feel sorry for putting a burden on others
11	Feeling about the high medical costs borne by the local and central governments

（7）Sixth Interview Item

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Estimated time	Interviewer
2 minutes 42/60	Q6-1: Of the "health issues," "effects on daily life," and "effects on emotions and feelings" about which you talked to me, what do you think is the most undesirable? What are the top 3 most undesirable items? If fewer than 3 items, proceed to the Eighth Interview Item after Questions 6-2 or 6-3.
2 minutes 44/60	Question 6-2: I would like to ask about the first item. Why do you think that XX is not desirable? If it is difficult to give an answer, it is not a problem, and you don't have to force yourself to answer. Please ask the specific reasons concerning the health-related items and their effects mentioned so far. If the reasons are not specific, delve into them with additional questions.
2 minutes 46/60	Question 6-3: I would like to ask about the second item. Why do you think that XX is not desirable? If it is difficult to give an answer, it is not a problem, and you don't have to force yourself to answer.
2 minutes 48/60	Question 6-4: I would like to ask about the third item. Why do you think that XX is not desirable? If it is difficult to give an answer, it is not a problem, and you don't have to force yourself to answer.
- minutes -/60	If the subject cannot narrow down to only 3 items, please ask the reasons for the fourth and subsequent items as well. Question 6-5: I would like to ask about the fourth item. Why do you think that XX is not desirable? If it is difficult to give an answer, it is not a problem, and you don't have to force yourself to answer.

（8） Seventh Interview Item

Estimated time	Interviewer
- minutes -/60	If the subject is in good health and did not answer anything about undesirable conditions in the sixth interview item, or only answered one or two items, ask the subject what areas of daily life and emotions would be affected if his/her health were to deteriorate.
	Q7-1: If PNH symptoms cause deterioration of your health or increase the burden of the treatment, how do you think it will affect your daily life and emotions? If your health were to deteriorate, which areas of your daily life do you not want to be affected? Please explain the reason. Please explain [For the Subject (4) Areas of Daily Life] and [For the Subject (5) Areas of Emotions] to the subject by presenting examples.

（9） Eighth Interview Item

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Estimated time	Interviewer
2 minutes 50/60	Please explain [For the Subject (6) Desirable and Undesirable Treatments] to the subject by presenting examples. Interview the subject about desirable and undesirable treatments. Question 8-1: There are several ways to administer drugs such as oral administration and injection for PNH and other diseases. Which of these treatments are desirable and which are undesirable to you? You may be concerned about forgetting oral and self-injection treatments because you need to administer them yourself. Injection treatments may cause a slight tingling or swelling at the injection site, and treatments by infusion drip may be a burden because they take a longer time. If the subject has questions about efficacy and safety, please tell him/her that they are the same. In [For the Interviewer (7) Desirable and Undesirable Treatments], please mark a circle in the column of the desirable or undesirable treatments indicated by the subject. (Multiple responses may be selected if the subject wishes to. If there are multiple responses, please enter their priority [e.g. 1st, 2nd]).
5 minutes 55/60	Question 8-2: I would like to ask about the desirable treatment you prefer. Why did you think that XX is desirable? If there are any comments on the items of [For the Interviewer (8) Areas of Daily Life] and [For the Interviewer (9) Areas of Emotions] among the responses of the subject, please mark a circle in the column of "Spontaneously Expressed." If there are no categories, please fill in the content in the free text box below.
	Please ask about the areas of daily life and the areas of emotions that have the subject did not mention in Question 8-2. Please explain [For the Subject (7) Areas of Daily Life] and [For the Subject (8) Areas of Emotions] to the subject by presenting examples. In today's interview, we have asked how your "health issues" affect your "daily life" and "emotions and feelings." Please take a moment to review the list you saw during the interview. Please ask the subject about areas that are not marked with a circle for "Spontaneously Expressed" in Question 8.2. Question 8-3: Are there any "daily life" or "emotions or feelings" that have influenced the reason why you thought XX is desirable? If so, what kind of effect is it?

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	For any comments by the subject, please mark a circle in the column of "Responded to Follow-Up Probes."
5 minutes 60/60	Question 8-4: I would like to ask about the undesirable treatment you selected. Why do you think that XX is not desirable? If there are any comments on the items of [For the Interviewer (8) Areas of Daily Life] and [For the Interviewer (9) Areas of Emotions] among the responses of the subject, please mark a circle in the column of "Spontaneously Expressed." If there are no categories, please fill in the content in the free text box below.
	Please ask about the areas of daily life that are not mentioned by the subject in Question 8-4. Please explain [For the Subject (7) Areas of Daily Life] and [For the Subject (8) Areas of Emotions] to the subject by presenting examples. In today's interview, we have asked how your "health issues" affect your "daily life" and "emotions and feelings." Please take a moment to review the list you saw during the interview. Please ask the subject about the areas of emotions that are not marked with a circle for "Spontaneously Expressed" in Question 8.4. Question 8-5: Are there any "daily life" or "emotions or feelings" that have influenced the reason why you thought XX is undesirable? If so, what kind of effect is it? For any comments by the subject, please mark a circle in the column of "Responded to Follow-Up Probes."

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[For the Interviewer (7) Desirable and Undesirable Treatments]

Select an option from each of the 3 tables below:

Number	Desirable	Undesirable	Item
1			Don’t forget to take tablets or capsules once daily at the designated time each day
2			Don’t forget to take the tablets or capsules twice daily at the designated time each day
3			Don’t forget to take tablets or capsules 3 times a day at the designated time each day
4			Don’t forget to administer a self-injection at home once a month taking a few minutes
5			Every time you visit the hospital, medical personnel will administer an injection like a prophylactic vaccine into an arm within a few minutes
6			Every time you visit the hospital, medical personnel will use a small device to administer an injection into the abdomen over approximately 20 minutes
7			Every time you visit the hospital you will receive an intravenous drip over approximately 30 minutes

Number	Desirable	Undesirable	Item
1			Visit the hospital every 2 weeks
2			Visit the hospital once a month
3			Visit the hospital every 2 months
4			Visit the hospital every 3 months

Number	Desirable	Undesirable	Item
1			Visit a far-away hospital with a specialist
2			Visit a nearby hospital with a family doctor

Supplementary file2

[For the Subject (6) Desirable and Undesirable Treatments]

Select an option from each of the 3 tables below:

Number	Item
1	Don’t forget to take tablets or capsules once daily at the designated time each day
2	Don’t forget to take the tablets or capsules twice daily at the designated time each day
3	Don’t forget to take tablets or capsules 3 times a day at the designated time each day
4	Don’t forget to administer a self-injection at home once a month taking a few minutes
5	Every time you visit the hospital, medical personnel will administer an injection like a prophylactic vaccine into an arm within a few minutes
6	Every time you visit the hospital, medical personnel will use a small device to administer an injection into the abdomen over approximately 20 minutes
7	Every time you visit the hospital you will receive an intravenous drip over approximately 30 minutes

Number	Item
1	Visit the hospital every 2 weeks
2	Visit the hospital once a month
3	Visit the hospital every 2 months
4	Visit the hospital every 3 months

Number	Item
1	Visit a far-away hospital with a specialist
2	Visit a nearby hospital with a family doctor

[For the Interviewer (8) Areas of Daily Life]

Number	Spontaneously Expressed	Responded to Follow-Up Probes	Item
1			Movement (walking, running)
2			Cleverness (using the fingers or fingertips)
3			Daily life inside the house, such as housework

Supplementary file2

4			Daily life outside the house such as going out
5			Work and study
6			Relationships with family, friends and relatives
7			Relationships with colleagues and others at work, and other people
8			Independence (not being a burden to others, including family, friends, and people who are not close)
9			Daily self-management of physical condition
10			Unable to do what I wanted to do due to treatment
11			Overall quality of life
[Free text box]			

[For the Subject (7) Areas of Daily Life]

Number	Item
1	Movement (walking, running)
2	Cleverness (using the fingers or fingertips)
3	Daily life inside the house, such as housework
4	Daily life outside the house such as going out
5	Work and study
6	Relationships with family, friends and relatives
7	Relationships with colleagues and others at work, and other people
8	Independence (not being a burden to others, including family, friends, and people who are not close)
9	Daily self-management of physical condition
10	Unable to do what I wanted to do due to treatment
11	Overall quality of life

[For the Interviewer (9) Areas of Emotions]

Supplementary file2

Number	Spontaneously Expressed	Responded to Follow-Up Probes	Item
1			Become anxious or scared
2			Become sad or pessimistic
3			Feeling disgusted or uncomfortable with myself (self-denial)
4			Feeling frustrated and angry with myself or others
5			Feeling distressed and suffering
6			Think it would be good to maintain the present situation
7			Feel dissatisfied
8			Feel shame (embarrassed, ashamed)
9			Become disgusted with life-long treatment
10			Feel sorry for putting a burden on others
11			Feeling about the high medical costs borne by the local and central governments
[Free text box]			

[For the Subject (8) Areas of Emotions]

Number	Item
1	Become anxious or scared
2	Become sad or pessimistic
3	Feeling disgusted or uncomfortable with myself (self-denial)
4	Feeling frustrated and angry with myself or others
5	Feeling distressed and suffering
6	Think it would be good to maintain the present situation
7	Feel dissatisfied
8	Feel shame (embarrassed, ashamed)
9	Become disgusted with life-long treatment
10	Feel sorry for putting a burden on others
11	Feeling about the high medical costs borne by the local and central governments

（10）End

Supplementary file2

Estimated time	Interviewer/Receptionist
1 minute 60/60	That's all for today's interview. Question: Is there anything you would like to say or add that was not discussed in today's interview? Please wait a while and consider if there is anything you want to say. Thank you very much for your time today. It was a very useful interview. We will send a reward of our appreciation to your registered address later.