Appendix C. Interview guide

Interview data

Study ID	
Interview Date (day/month/year)	
Interview Location	
Interviewer	
Length of Interview (minutes)	
Treatment decision	
Decision analysis result	
Concordant or discordant?	

Introduction

Hello, my name is (*name*) and I am the (*position such as research coordinator, research assistant*) on the [name of study]. The purpose of this interview is to learn about how you made the decision regarding whether or not to take heparin during your pregnancy. The interview today will last approximately 30 minutes.

We are most interested in learning about your personal experience with heparin and how you came to your treatment decision. There are no right or wrong answers.

Your participation is completely voluntary, and we can stop the interview at any time. The information from this interview will remain confidential and will not be shared with your care provider.

Interview Questions

The questions in this interview are divided into four categories and will explore your experiences and perceptions as they relate to: 1) your decision-making process; 2) the direct choice exercise; 3) the personalized decision analysis; and 4) your knowledge about preventive treatment with heparin.

1.0 Decision-Making Process	**As part of this study you were asked to make a decision about taking heparin during your current/future pregnancy to prevent blood clots.**
	1.1 What is your preferred level of engagement when it comes to making a clinical decision? For example, do you prefer to have your health care provider make the treatment decision or do you do your own homework?

[If no reaction from the woman, we could provide an example (e.g. "for example, do you prefer to have your health care provider make the treatment decision or do you do your own homework and ask questions?")]

1.2 Please describe to me the process you used to make your decision about heparin, which in your case was to **take/not take** heparin?

1.3 What types of information did you use to make your decision? [Try to discover previous knowledge/experience or personal research conducted on own]
   a) Which information was most helpful in informing the decision you made?
   b) Which information was the least helpful in informing the decision you made?

[If no reaction from the woman, we could provide an example (e.g. "for example, the decision aid had descriptions of relevant health outcomes" or "do you ask the doctor questions, review pamphlets, look up information online")]

1.4 What factors do you think that influenced your final decision?
   a) Are there any personal factors that influenced your decision? These can include your values, preferences, concerns, or previous experiences with treatment.
   b) Are there factors related to your health care provider that influenced your decision?
   c) Are there other factors prior to completing the direct choice or personalized decision analysis exercise today that influenced your decision?

1.5 What was the experience of being asked to make this decision like for you? [For all responses, follow up with a "why?" question]
   a) At any point in time, did you experience feelings of confusion during the decision-making process? [if yes, have them describe when they experienced confusion]
   b) What strategies did you use to address these feelings of confusion?

1.6 Once you made your final decision, how confident did you feel about the decision you made?
   a) What factors increased your level of confidence and why?

1.6 Please explain to me how comfortable you are with the decision you made? Why?

2.0 Decision Using Direct Choice

As part of this study, you participated in a direct choice exercise in which you were presented with information about the risks and benefits of treatment along with different health outcomes.

2.1. Was the amount of information provided in the direct choice exercise appropriate? Why?

2.2. Did you have a clear understanding about the risks and benefits of heparin after completing the direct choice exercise?
   a) Could you review the information and explain aloud the risks and benefits of treatment using actual numbers?

2.3. How did you weight the different aspects of information that were presented (e.g. the risks of experiencing another blood clot versus your personal preferences)?
   a) Could you explain your rationale?

2.4. What ultimately drove your decision to **take/not** take low molecular weight heparin during your pregnancy?

2.5. What was the overall experience like for you in making a decision after the direct choice exercise?

3.0 Decision Analysis Process

Following the direct choice exercise, you received the results from your personalized decision analysis. Decision analysis involves asking you about your preferences for health outcomes related to the treatment decision. Using a mathematical formula, we then combine this information with the risk probability of each health outcome to formulate a treatment recommendation. This recommendation is based on a score that takes into account the likelihood of each health outcome occurring and the importance you assigned to them. It indicates whether a treatment is likely to lead to an increase or decrease in your quality of life.

3.1a Please describe your experience with the rating scale, feeling thermometer and gamble exercises that we completed.

3.1b Did these exercises help clarify your personal preferences for the different health outcomes (e.g. experiencing a blood clot)?

3.1c Do you think these exercises reflected your personal preferences?

3.2 What were your thoughts and reactions when you were told the results from the personalized decision analysis process?

CONCORDANT DECISIONS [The research assistant would get the information on concordant and discordant decisions from the table at the beginning of the interview guide]

3.3a For you, there was consistency between the decision you made after the direct choice exercise and the results from the decision analysis process.

After reviewing treatment information, YOU made the decision to **take/not take** heparin. The result of the decision analysis also supported this decision to **take/not take** heparin

How did this consistency make you feel? Why?

DISCORDANT DECISIONS: [as above, the research assistant will explain the discordance to set the context]

3.3b For you, there was a difference between the decision you made after the direct choice exercise and the results from the decision analysis process.

After reviewing treatment information, YOU made the decision to **take/not take** heparin while the result of the personalized decision analysis recommended that you **take/not take** heparin. We would like to insist on the fact that there is no right or wrong decision in this context.

Having said this, the discordant decision could reflect a difference between the methods we used to formulate a treatment recommendation with the mathematical formula and the factors you considered as a patient.

Our objective is to identify the cause of this difference. We would like to start by ask how did this inconsistency make you feel? Why?

If the participant modified her initial decision:

3.4a   Please explain why you changed your decision after receiving the results from the decision analysis?

3.4b   How do you think the results from the decision analysis influenced your levels of confidence or comfort with your final decision?

3.4c   Did you find having the results of the decision analysis useful for making your decision?

3.4d   Would you find having the results of a decision analysis useful for making other difficult health care decisions?

3.4e   Would you have preferred to have only gone through the personalized decision analysis exercise instead of making the decision yourself first with the decision aid? In other words, would you rely on the personalized decision analysis exercise rather than making the decision by yourself?

If the participant did not modify her initial decision:

3.4f   Please explain why you maintained your decision after receiving the results from the personalized decision analysis?

3.4g   How do you think the results from the personalized decision analysis influenced your levels of confidence or comfort with your final decision?

3.4dh   Did you find having the results of the decision analysis useful for making your decision?

3.4i   Would you find having the results of a personalized decision analysis useful for making other difficult health care decisions?

3.4j   Would you have preferred to have only gone through the decision analysis exercise instead of making the personalized decision yourself first with the decision aid? In other words, would you rely on the personalized decision analysis exercise rather than making the decision by yourself?

4.0 Treatment Knowledge

To finish, we have some quick questions regarding your knowledge of heparin. Throughout this study, you have been provided with information about the use of heparin to potentially reduce the risk of blood clots during pregnancy.

4.1   From your perspective, what are the benefits of treatment, which involves daily injections of heparin throughout pregnancy, to prevent blood clots?

4.2   From your perspective, what are the potential drawbacks related to daily injections of heparin throughout pregnancy?

4.3   Is there any additional information that you would like to share about the process of making a decision about treatment for blood clots?