

Appendix 4: Patient interview guide

Instructions for interviewer:

This section is a semi structured, open-ended interview. Use the questions here to guide the conversation. Probes are provided to help you explore the questions with the participant and to provide some bearing on what is important to explore in the conversation. Your questions may branch into other topics not covered in the interview questions. This information is important as well and it is ok to depart from the interview questions in order to explore these elements. Before ending the interview review the questions provided here to be sure you discussed all of the topics outlined.

Hello [participant]. Thank you very much for your participation in this study. Your participation is completely voluntary, you can stop at any time and you can opt out of any questions you do not wish to answer or discuss. We ask you not to use your name, or the names of any relatives or other individuals, in this interview. Your answers are confidential. Once this interview is completed we will have it transcribed, at which time we will remove any references to names or places that could identify you. Once the transcription is verified we will erase the audio recording. Please note that if for any reason in this interview you inform us of your intent to harm yourself or other we will have to report this information.

We are interested in learning more about your experiences receiving genome sequencing results.

I am going to begin recording the interview now. [Turn on audio recorder]

Topic: Genome Sequencing Results

1. To get started, could you please tell me a bit about your motivations for learning genome sequencing results from the GENCOV study?
 - a. What did you expect to learn? What did you expect to do with your results?
2. Could you tell me about your experience receiving your results from genome sequencing?
 - a. What types of results did you learn?
 - b. What was most important to you?
 - c. How did the results make you feel initially?
 - d. How did your thoughts about your results change over time?
 - e. How did you feel about the format of the report? Do you have any suggestions for improvement?
3. What did you find useful about your genome sequencing results?
 - a. Why was that useful for you?
 - b. [If participant states they did not find results useful] Why did you find the results to not be useful?
 - c. Since you have learned your genome sequencing results, how has it helped explain anything in your personal or family health history, if at all?
4. What actions did you take based on your genome sequencing results?

- a. How did you or your healthcare providers use your results to manage your medical care?
 - b. How did you feel about changes in your medical care that were made based on your genome sequencing results?
 - c. What were challenges that you faced in acting on your genome sequencing results (e.g., accessing health care)?
 - d. How did you use the results in other aspects of your life?
 - e. How are you planning to use your results in the future?
5. Genome sequencing results are associated with some level of uncertainty. For example, even if you get a result that indicates you are at higher risk for a disease, you won't necessarily get the disease. What are your thoughts about this uncertainty?
- a. How does this uncertainty make you feel?
 - b. What were you uncertain about when acting on your results?
6. Now, I am interested in learning about your experiences talking about your genome sequencing results with family members.
- a. Which family members did you share your results with?
 - b. How did you decide who to share your genome sequencing results with?
 - c. What were your experiences sharing your results?
 - i. What challenges did you face in sharing the results with people?
 - ii. What did you find helpful in sharing results with people?
 - d. Who are you thinking about sharing the results with in the future?
7. What were any negative experiences that you had after receiving your genome sequencing results?
8. What were any positive experiences that you had after receiving your genome sequencing results?
9. Over time, as we learn more about the genetics of disease, the meaning of your genome sequencing results could change. How does this make you feel?

Topic: Viral Lineage Results

1. Now, I would like to talk about your viral lineage results. What did you learn from these results?
2. How did you feel when you learned your viral sequencing results?
3. What did you find useful about learning these results?
 - a. **Probes:** Why was that useful for you?
 - b. [If participant states they did not find results useful] Why did you find the results to not be useful?
4. How have you used your viral lineage results?
 - a. **Probes:** In your healthcare? In other areas of your life?
5. Who have you spoken with about your viral lineage results?

Topic: Polygenic Risk Score Results

Now, I would like to talk about your polygenic risk score results.

1. What did you learn from these results?
2. How did you feel when you learned your PRS results?
3. How do you interpret your risk for [colorectal cancer, breast cancer, prostate cancer, type II diabetes, coronary artery disease, atrial fibrillation]?
4. How have you used your PRS results?
 - a. **Probes:** How have you used your results in your healthcare? How have you used your results in other areas of your life, for example changes to your exercise, diet, or other behaviours? Changes to your future plans? How do you think you may use your PRS in the future?
5. Who have you spoken to about your PRS results?

Topic: Ancestry Results

Now, I would like to talk about your ancestry results.

1. What did you learn from these results?
2. How did you feel when you learned your ancestry results?
3. What have you found useful about learning your ancestry results?
 - a. **Probes:** Why was that useful for you?
 - b. [If participant states they did not find results useful] Why did you find the results to not be useful?
4. How accurate do you feel the ancestry results are?
 - a. **Probe:** Do you feel like the reported ancestry results are aligned with your self-reported ancestry?
5. How have used your ancestry results?
6. Who have you spoken to about your ancestry results?

Topic: Blood Group Results

Now, I would like to talk about your blood group results.

1. What did you learn from these results?
 - a. **Probes:** Was this information new to you?
2. How did you feel when you learned your blood group results?
3. What have you found to be useful about learning your blood group results?
 - a. **Probes:** Why was that useful for you?
 - b. [If participant states they did not find results useful] Why did you find the results to not be useful?
4. How did you use your blood group results?
 - a. **Probes:** Blood donations? Transfusions? Update medical records?
5. Who have you spoken to about your blood group results?

Topic: HLA Results

Now, I would like to talk about your HLA results.

1. Now, I would like to talk about your HLA results. What did you learn from these results?

2. How did you feel when you learned you HLA results?
3. What have you found to be useful about learning your HLA results?
 - a. **Probes:** Why was that useful for you?
 - b. [If participant states they did not find results useful] Why did you find the results to not be useful?
4. How have you used your HLA results?
5. Who have you spoken to about your HLA results?

Topic: Serology Results

Now, I am interested in learning about your experiences receiving your antibody results from the GENCOV study.

1. Now, I am interested in learning about your experiences receiving your antibody results from the GENCOV study. What was that experience like for you?
 - a. **Probes:** What motivated you to want to learn your antibody results?
2. What did you learn from your antibody results?
3. How did you feel when you learned your antibody results?
4. What have you found to be useful about knowing your antibody results?
 - a. **Probes:** Why was that useful for you?
 - b. [If participant states they did not find results useful] Why did you find the results to not be useful?
5. How have you used you use your antibody results?
 - a. **Probes:** In your healthcare? In other areas of your life? To inform decisions about being vaccinated? To inform decisions about social distancing?
6. Who have you spoken with about your antibody results?
 - a. **Probes:** Have you discussed these results with your family doctor?

Topic: Closing questions

1. Knowing what you know now, would you learn these results again? Why or why not?
2. Is there anything else you wish to share, that we haven't covered?

Interviewer: Turn off the recorder and thank the participant.