

Supplementary file 2

Genetics Adviser: evaluating a digital decision support tool for genetic results
Appendix 12 – Qualitative Interview Guide

Qualitative 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. 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. Direct quotes from your responses to question in this interview may be used in reports or publications, but the quotes will not be attributed to you or contain any information that could be used to identify you. These quotes will be found in publications about the study results and most of these publications can be accessed on line.

The interview will take about 60 minutes to complete. Although we do not anticipate it, our discussion today may include topics that you may find sensitive and you might find some questions uncomfortable. You are free skip any question you prefer not to answer.

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

We are interested in learning about your experience using the digital tool and learning your clinically significant findings from genomic sequencing.

Topic: Using the digital tool

First, I'd like to learn more about your experience using the digital tool.

1. Please tell me about your experience using the digital tool?

Probes:

- *What did you like about using the digital tool?*
- *What did you dislike about using the digital tool?*
- *What did you do after you had used the digital tool (e.g. call clinician, look online for more information)*
- *How did the digital tool influence your decision?*
- *What do you wish had been different about your decision making process?*

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2. What were your thoughts about the volume of information presented in the digital tool?

Probes:

- *What other information would you have wanted?*
- *What information seemed unnecessary or not useful?*

3. What were your thoughts about how information was presented in the digital tool?

Probes:

- *What made it easy to understand?*
- *What made it difficult to understand?*
- *What changes would you suggest to formatting or to the presentation of information (e.g. audio, visual, text)?*

4. What made it easy to use to the digital tool to (e.g. accessing the digital tool, navigating the digital tool)?

- *E.g. easy to access, easy to navigate.*

5. What were challenges to using the digital tool?

6. What changes would you suggest be made to improve the digital tool?

Probes:

- *Additional features?*
- *Additional information?*
- *A different presentation of the information?*

Topic: Digital tool implementation

Now, I am going to ask some questions related to using digital tools more widely in clinical care.

7. What do you see as the benefits of a digital tool like this one being used regularly in clinical care to help patient make decisions about genetic testing?

8. What concerns do you have about a digital tool being used regularly in clinical care to provide updates to patients?

9. What do you see as facilitators to using digital tools in clinical care?

Probes:

- *Are the facilitators specific to the patient portal?*
- *Are the facilitators specific to the patients or health professionals?*
- *Who will use the patient portals and include them in the process of care?*

10. What do you see as being challenges to using portals in clinical care?

Probes:

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- *Are the barriers specific to the digital tool (e.g., requires computer access, literacy too high, too difficult to use, not accessible)?*
- *Are the barriers specific to the patients or health professionals (e.g. lack of awareness, limited knowledge/skills, attitudes, concerns, incompatible with current practice, lack of confidence)?*
- *Who will use digital tools and include them in the process of care?*

Topic: Learning results from genomic sequencing

Now, I would like to ask you some questions about what it was like to learn results from genomic sequencing.

11. What was your motivation for participating in this study?

12. Before you got your results back, what was your expectation of the kinds of information you would learn from genomic sequencing?

Probes:

- *How was the experience of waiting for your results?*
- *What did you do or who did you speak with to prepare for receiving your results? Did you find these helpful?*

13. Please tell me about your experience receiving your results from the exome sequencing study.

Probes:

- *What results did you learn?*
- *What was most important to you?*
- *How did the results make you feel initially?*
- *How did your thoughts about your results change over time?*

14. What did you find useful about your results?

Probes:

- *Why was that useful for you?*
- *[If participant states they did not find results useful] Why did you find the results to not be useful?*
- *[For positive primary/secondary or incidental results] What does this disease risk [Interviewer: state disease risk mean for you and your family?]*
- *How do you feel about learning these results?*
- *Since you have learned your results, how has it helped explain anything in your personal or family health history, if at all?*

15. As you learned in the study, all results come with some level of uncertainty. E.g. Even if you get a result, you won't necessarily get the disease. If you don't get a result, that doesn't mean you are not at

risk for genetic diseases. What uncertainty did you experience with respect to your genome sequencing results?

Probes:

- *How did you feel about this uncertainty?*
- *[If applicable] Some of your results are in genes associated with a high risk of disease [Category 1, 3, 4], whereas others are associated with a low risk for disease [Category 2]. How does this affect how you think about your results?*
- *[If applicable] For some of your results, we can't say exactly what your risk of disease is, just that it is higher than average. What does this mean to you? How do you feel about this?*
- *Incidental findings may not be able to tell you how severe a disease will be, if you do develop it. What are your thoughts about this?*
- *What were you uncertain about when acting on your results?*

16. How did you decide to share or not share results with other people?

Probes:

- *What were your experiences sharing your results?*
- *What challenges did you face in sharing the results with people?*
- *What did you find helpful in sharing results with people?*
- *How did your family members feel about the results?*
- *How did your family members use the results?*
- *Who are you thinking about sharing the results with in the future?*

17. What actions did you take based on your results?

- *How have you or your healthcare providers used your results to manage your medical care? [Probe each result]*
- *How did you feel about changes in your care based on your results?*
- *Were there other things you wanted to do with your results, that your medical specialists would not do for you?*
- *What were challenges that you faced in acting on the results?*
- *What are challenges you faced in accessing health care (screening, surgery) related to your results?*
- *Have you discussed your results with your family doctor? If so, how did your family doctor manage your results? [If they have not discussed their results with their fam dr] Why have you not discussed your results with your family doctor?*
- *[If they had a referral to a specialty clinic] I understand you were referred to [clinic] because of your findings. Could you please tell me about that experience?*
- *What actions were taken, what did you learn, what ongoing follow up was recommended*
- *How do you feel about the process of receiving care?*
- *How do you feel about the outcomes of this care?*

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- *[If they did not pursue the recommended referral] Why did you choose not to pursue a referral to [clinic] because of your result?*
- *How have you used the results in other aspects of your life? E.g. coping with disease risk, ability to plan for future (e.g. financial), change outlook on life, overall quality of life, value of having information about your health*
- *How are you planning to use your results in the future?*

18. What were any negative experiences that you had after receiving your results?

Probes:

- *Discrimination?*
- *Privacy issues?*
- *Stigma?*

19. What were any positive experiences that you had after receiving your results?

20. Over time, as we learn more about the genetics of disease, the meaning of your results could change.

Probes:

- *How do you feel about that?*
- *What are your expectations about being recontacted with updated results?*
- *What types of results would you want updates about?*
- *How would you want to be recontacted? By whom?*
- *How would you feel if your results were updated through an online portal?*
- *What would you like about this process?*
- *What would you be concerned about?*

21. Knowing what you know now, would you do this test again? Why or why not?

Topic: Closing Question

22. Is there anything you would like to share, that we have not yet covered?