FAMILY COMMUNICATION SURVEY QUESTIONS

1. Since receiving your study results, have you shared the information with any biological family members (blood relatives)?

- ○ Yes
- ○ I didn't share this information with anyone [If selected, skip to Q5]
- ○ I haven't shared this information yet, but plan to in the future [If selected, skip to Q3]
- ○ I don't have blood relatives to share this information with [If selected, skip all remaining questions]

2. Since receiving your study results, have you shared the information with any of the following blood relatives?

	Yes	No	N/A
My child(ren)	○	○	○
My siblings	○	○	○
My parents	○	○	○
My other biological family members [If select "Yes":] Please specify who: [FREE TEXT]	○	○	○

3. On a scale of 1 to 5, how important were each of the following reasons for sharing your genetic test results with blood relatives?

	Not at all important (1)	2	3	4	Very Important (5)
To give my blood relatives information about their genetic risk	○	○	○	○	○
To encourage my blood relatives to have genetic testing	○	○	○	○	○
The doctor/genetic counselor encouraged me to share the information with blood relatives	○	○	○	○	○
So my relatives could make family planning decisions	○	○	○	○	○
To share the information I learned because I thought it was interesting	○	○	○	○	○
To share my feelings about my genetic test results	○	○	○	○	○
So I could get help from blood relatives with coordinating and planning for things like appointments and other health-	○	○	○	○	○

related responsibilities (for example, going to doctors' appointments, getting child care, getting transportation, etc.)					

4. Are there any other reasons that influenced your decision to share the results with blood relatives? [FREE TEXT]

5. On a scale of 1 to 5, how important were each of the following reasons for not sharing your genetic test results with blood relatives?

	Not at all important (1)	2	3	4	Very Important (5)
I don't want to worry or upset them	○	○	○	○	○
I would have to talk to a blood relative I'm not close to/prefer not to talk to	○	○	○	○	○
I don't have contact information for my blood relatives	○	○	○	○	○
I have privacy concerns about sharing this information with my relatives	○	○	○	○	○
I don't know how to explain the genetic results to my relatives	○	○	○	○	○
I don't think this information is useful for my relatives	○	○	○	○	○
I'm having trouble coping with my results	○	○	○	○	○
I'm overwhelmed with my health	○	○	○	○	○
I'm worried that my relatives will treat me differently	○	○	○	○	○

6. Are there any other reasons that influenced your decision not to share the results with blood relatives? [FREE TEXT]

7. What type of information did you share with blood relatives? Please check all that apply.

- ☐ General information about my study results
- ☐ Detailed information about the genes they tested
- ☐ My relative's risk of having a condition
- ☐ Information about the possibility of being treated unfairly based on the study results
- ☐ Recommendations of ways to prevent illness
- ☐ Recommendations for more screening and testing

- ☐ Feelings about my study results
- ☐ Other, please specify: [FREE TEXT]

8. How did you share information about your genetic test results with your blood relatives? Please check all that apply.

- ☐ In person
- ☐ By phone
- ☐ By letter
- ☐ By email
- ☐ Through social media
- ☐ Other, please specify: [FREE TEX]

INTERVIEW GUIDE FOR TIMEPOINT #1: within 1 month post-disclosure

I. Warm-up & Background

A. Personal background/Approach to health

1. It would be great if you could start by telling me a bit about yourself. Learning a little about you, things like where you are from, your family, what you do, helps me put into context some of the things we'll discuss later in the conversation.

2. What are your biggest concerns about your health?
    a. What are the ways you feel you are able to take care of your health?
    b. My understanding is that you receive health care services through [DH/KP]. Has that always been the case?
        i. If not, how has your experience receiving health care changed since you were at ___ and now that you are at [DH/KP]?
        ii. Do you go to the doctor regularly? Do you go with family members to their appointments? Etc.
        iii. What role does your doctor play in your decisions about your healthcare?

3. We're interested to know how families communicate about health.
    a. When you think of family, who do you include?
    b. How open would you say you and your family are when it comes to sharing health issues that might affect one of you?
    c. [If open] Can you give me an example of when someone in the family had a health problem? What did you talk about?
    d. [If not open] Why do you think that is?
    e. What about cancer? Is that the same or different as other health issues when it comes to talking about it in your family?
    f. [If no one has had cancer] How do you think your family would talk about cancer? Would it be the same or different from other health problems?

4. Prior to joining the CHARM study, what did you know about genetics or genetic testing? [if no familiarity, skip to Q6]

5. Have you or anyone in your family had a genetic test before this study? If so, what it was for? What were the results?

6. Before this study, was "hereditary cancer" or cancer running in the family something that you thought about? Tell me about that.

B. Enrollment in CHARM, familiarity with genetics, & preparation for results

7. Before we talk about your experience with the genetic counselor who gave you your test results, can you tell me a little bit about why you decided to join the CHARM study?
    a. What did you hope to learn by participating in the study?

8. Had you considered having genetic testing prior to joining CHARM?
    a. Was there anything that prevented you from getting it before?
    b. How important was it to you to get the information about cancer?
    c. How important was it to get the information about the other conditions on the test?
    d. What concerns or hesitations did you have about learning the information provided in the study?

9. When you signed up or while you were waiting for the test results, did you talk to any family or friends about participating in the CHARM study?
    a. If so, who? How did you explain the study and what you expected to get out of it?

10. How much were you thinking about the test results while you were waiting? Would you say a lot or not so much? Can you tell me about that?

11. How prepared did you feel to get the results? [If not very prepared, what do you think would have helped you to feel more prepared?] What helped you to prepare?

II. Return of results

A. Meaning of the results and care recommendations [Questions to be tailored based on test result and conversation with the the CHARM study genetic counselor]
Now let's talk about your conversation with the CHARM study genetic counselor who gave you your results.

12. What do you remember about the results the [GC name] gave you? [If GC used gene name, ask about that]
    a. What part of what she/he said was new information for you?
    b. For you, what was the most important thing the GC said during the call?

13. For those with VUS results: The GC described your test result as [remind participate how GC described results using GC's specific language or phrasing]…

        a. What do you think about that? How do you feel about getting that kind of result?

b. [If GC said this] The GC said that your test results might not have a negative impact in your health, but she/he wasn't sure. What was your understanding of what she/he said?
c. What do you think about the fact that doctors and scientists don't know yet what your specific test results mean, but that they might know in the future?
d. In the field of genetics, there's some debate about whether it makes sense to even give those results to the participants in genetic research, or whether it makes more sense just to wait until there's clarity about those genes. I'm curious about what you think about that, and whether you glad she told you about it (the uncertain result) at this point?

14. Now that you have your results, how do you understand your chances of getting cancer? [OR if participant has already addressed this]: In what ways, if any, has your participation in the study changed the way you think about your chances of getting cancer? how so?
    a. [If participant understands they are at high risk] Is that because the GC gave them a number? How much higher do they think their chances are? What does that number mean to you? [or if the GC said higher than average or a little higher, ask what that phrase means to you in terms of your risk?]

15. What did the GC recommend that you do next, now that you have this information about your chances of getting cancer?

B. Perceptions and understanding of communication with the GC

One of our goals is to learn more about how genetic counselors like the one you spoke to can communicate these test results in a way that is most useful for patients like you.
One challenging aspect of talking about genetics is that it can be complex and technical, and a lot of patients don't have a lot of knowledge or familiarity with it.

16. Was there anything that made it challenging to understand what the GC was saying? (Probes: Did the GC use words that you had not heard before and the GC was not clear at explaining them? Was it too much information to process?)

17. How complex or technical did the conversation seem to you?
    a. If not, was there anything that the GC did or said that made it easier for you to understand what she/he was saying? (e.g., spoke slowly, used simple language to explain things, asked questions to be sure you understood what she/he was saying)
    b. If so, what made it challenging? (e.g. used technical language, too much explanation/information, information not relevant) [ask about participant's understanding of specific words, phrases or concepts]
    c. What did you do if the GC said something that you didn't understand?

d. I noticed you asked a lot of questions/didn't ask a lot of questions. How comfortable did you feel asking the GC questions? If not, why not?
    i. How comfortable do you feel generally asking questions when talking with a medical provider? If not, why not?

Another aspect of the communication/that might have made the communication challenging is that it was on the phone; you might be driving or doing something else while talking or the connection might not be great.

18. How was it for you to get these test results over the phone?
    a. How do you think it would have been different if it had been in person?
    b. What were the advantages of having it on the phone for you?
    c. What were the disadvantages?

Some people have told us that when the GC called them, they were distracted or the GC used words they didn't understand.

    a. Did you get the call when you were distracted with other things?
    b. After you heard that your test was positive, was it hard to listen to the rest of the information that the GC was providing?
    c. What other experiences have you had with medical appointments by phone?

19. [For modified GC arm]: describe whatever teachback GC used] At one point the GC asked you to talk about what she/he had said so she/he would know she/he was doing a good job.
    a. How did you feel about that?
    b. Were you familiar with that technique?

20. [For usual care GC arm] When the GC asked if you had any questions, you said…(ask about this)

21. Overall, how comfortable did you feel with the GC?

    a. What do you think were the reasons you felt that way?
        i. Was there anything that the GC said or did that helped put you at ease?
        ii. Was there anything that the GC said or did or didn't say/do that made you feel worried?
    b. Aside from the things you just mentioned, would you have liked the GC to do anything different? [If so, what was it?]

22. What kind of support did the GC offer you during the phone call?

23. The GC recommended you do [X]. What do you think is most important for you to do now?

    a. What do you plan to do? (e.g. talk to family, talk to PCP, get a mammogram…)

24. Have you seen any providers since you received your test results?
    a. Do you have a primary care provider or other doctor you see regularly? Tell me about your relationship with your provider(s).
    b. Do you plan to talk to him/her? If so, what are you planning to tell her/him? What do you hope she/he will do?

25. How important are these results for your family members?

    a. [If don't know] Did the GC talk about that at all?

26. Have you or do you plan to share your test results with anyone in your family? If yes, How did those conversations go?
    a. If not, why not?
        i. i. Any reasons why you wouldn't talk to family members about this information?
        ii. ii. Some people find this information confusing or hard to explain. Would you prefer to have a GC (with your permission) talk to your family members who you want to have this information?
        iii. iii. Do you think you will in the future? How do you think those conversations will go? What will it be like for you to share these results.

V. Perceptions of interpretation and its impact *[for Spanish speaking participants]*

Now I'd like to learn about your experience with the interpreter who helped you communicate with the GC.

27. How was it for you to talk with the GC using an interpreter?

28. Genetics can be a difficult topic because it has a lot of medical terms that we don't hear in everyday life. How confident did you feel in the interpreter that you got? Why?
    a. Would you choose to have this interpreter again? why/why not?
    b. I noticed you asked for clarification/did not ask for clarification…Were there times during the conversation when you had trouble understanding what the interpreter was trying to say?
        i. If so, did you ask the interpreter for clarification?
        ii. If not, why not?
    c. Do you wish you had asked for clarification at any point?

d. Have you ever been in a situation in which you were using an interpreter and you did not understand what the Interpreter was saying?
    i. If so, what did you do? Did you ask the interpreter to repeat the information? Or did you ask the interpreter to ask the doctor for clarification?

29. Do you typically use an interpreter when you see a medical provider?
    a. If no, why did you choose to use an interpreter in this case?
    b. In what ways was it similar or different from your other experiences?
    c. This appointment was by phone. Did that make it any more difficult for you to use an interpreter? Do you have experience with having medical appointments by phone?

30. How was the audio connection during your conversation with the GC? Did it affect how the conversation when between you, the GC, and the interpreter?

31. Sometimes when medical providers use an interpreter, patients feel that something in the translation is being lost. Have you had that experience?
    a. How did you feel about that on this call?

32. Was there anything that the GC or interpreter could have done to help you understand the information more clearly?

III. Wrap-Up

33. Overall, What do the test results mean for you?
    a. How does this genetic test result change your view of yourself (how you think about yourself) as healthy/not healthy/etc.? *(Note to interviewer: goal of this question is to try to understand if/how perception of identity has changed, e.g. did it confirm/validate something you already knew about yourself; lead you to look at yourself/your health differently).*

34. Think about the last time you received a test result from a doctor. What do you think is different about receiving a genetic test result compared to other kind of medical tests you get from your doctor?
    a. How significant is it to get a genetic test compared to another type of clinical test like cholesterol?

35. What questions or concerns have you had since you spoke with the GC?

a. What have you done, if anything to get your questions answered or concerns addressed? Anything else?

36. Did you receive anything in the mail from the GC? If so:
    a. What did you do with the materials she/he sent you? Did you have a chance to read them? Were they useful? Understandable?

37. Overall, how meaningful was it to get the genetic test results?
    a. How important was the way the GC provided information (how he or she talked to you about the test results)?
    b. Any regrets about joining the study and getting these test results?

Those are all the questions I have for you. Is there anything else you would like to share with me about your experience receiving your genetic test results?

INTERVIEW GUIDE FOR TIMEPOINT #2: six months post-disclosure

I. Warm-up

1. How have you been since we last spoke in [month/season]? Probe re: COVID related issues/impacts, including changes to insurance/health system and ability to get recommended f/u care; current life priorities and how these may have shifted in this context, e.g. talking to relatives re: cascade testing. [Can also integrate some of these questions into relevant sections below]
2. How has your health been? Any changes?
3. Any other big changes in your life since we last spoke? (If no answer, probe for big events that could impact access to or time for health care e.g. changed jobs, moved, issues with kids etc.)

II. Impact of Genetic Testing

It has been about 6 months since you received your genetic test results from the CHARM study. You received [X] test results, is that right?

1. Can you tell me a little bit about if and how having these test results have changed your health care or anything else in your life?
    a. Have you talked with any doctors in the past 6 months?
2. How has getting these results changed your view of yourself or your day to day priorities?

III. Understanding of and attitude toward recommended care and follow-up with PCP, GC, other specialists

1. What did the GC recommend that you do after s/he gave you your test results?
    a. What do you think about these recommendations? Do you think they make sense/are right for you? Did you understand what you were told to do? (Probe for uncertainty–it's okay to say you aren't sure)
    b. Have you followed up on these recommendations?
2. [If seeking recommended care], have you had any difficulty getting the [e.g. MRI, Mammogram, Colonoscopy, appointment with genetics etc.]?
3. Do you have a primary care provider or other doctor you trust/see regularly?
    a. Tell me about your relationship with your provider(s).
4. Have you talked to your primary care provider or any other providers about the recommendations that the GC gave you?
    a. If so, how did that conversation go?
    b. How knowledgable did your provider seem about your results/genetic testing/this type of genetic condition?
    c. How comfortable did your provider seem talking about it with you?

d. If not, how likely is it that you would bring this up the next time you see her/him?
e. What concerns do you have about talking with him/her?

5. What have you told [or will you tell] your primary care provider about what the GC said about cancer screenings or other care that she recommended?
6. [If no PCP] Are you planning to do what the GC recommended?
    a. [If not,] what stands in your way?
    b. [If yes,] [if they haven't already…] when or where are you planning to get the services or tests the GC recommended?
7. Did you receive anything in the mail from the GC? If so:
    a. What were they? What did you do with the materials s/he sent you? Did you have a chance to read them? Were they useful? If so, in what ways? Understandable?

IV. Family communication

Now I'd like to ask you about your experience sharing your genetic test results with members of your family.

1. Genetic testing is to see if a person, in this case you, is at a higher risk of a certain illness, but also to see if certain illnesses are being passed down in families. What do you remember about what your test result means for your family's health?
2. Have you talked with anyone in your family about your test results?
    a. [If spoke with family member] How did you tell them (phone/face to face/letter/etc,)? How did the conversation go? How did they respond to the information? [Note to interviewer: try to discern between just passing on the letter or info vs. having a conversation about the diagnosis]
    b. How did you explain to them what your genetic test results mean for your health?
    c. The counselor sent you a letter to give to family members along with your test results, is that right? Did you use that family letter when you talked to your family? Did you send that letter to anyone? Tell me more about that.
    d. If not, was there a reason why?
        i. Any reasons why you wouldn't talk to family members about this information?
        ii. Some people find this information confusing or hard to explain. Would you prefer to have a GC (with your permission) talk to your family members who you want to have this information?
    e. Were there any other materials or resources that you would like to have had to help with this discussion?
3. Have any of the family members you've told been tested? Or any planning to get tested?
    a. Through the study, or elsewhere? Why/why not?

    b. Did you tell your family members that they could get free genetic testing through the study?
    c. [for any family members tested] what was that process like for them? (How were the referred, where did they go, was it easy or challenging to get testing, etc.)
4. [If has not shared information with family] Are you planning to share this information with any family members?
    a. If not, tell me more about that?
    b. Are there any family members that you specifically do not plan to share this information with? If so, who and why?
5. What do you think the benefits of sharing this information with close family members are?
6. What are your concerns about sharing this information with them? How important do you think this information would be to them?
    a. What are the downsides?
7. Many people who get genetic test results say that their relationships with close family members change. Has that happened to you? If so, how has your relationship changed? Would you say for the better or the worse?

Wrap-Up

8. Overall, how do you feel about participating in this study and learning about your genetic information through a research study rather than your own doctor?

Those are all the questions I have for you. Is there anything else you would like to share with me about your experience receiving your genetic test results?