Puski, A., Hovick, S., Senter, L., & Toland, A. E. Involvement and Influence of Healthcare Providers, Family Members, and Other Mutation Carriers in the Cancer Risk Management Decision-Making Process of *BRCA1* and *BRCA2* Mutation Carriers. *Journal of Genetic Counseling*.

Online Resource 1: Qualitative Research Interview Guide

Part 1: Perceptions of Risk

Thank you for your willingness to participate in this interview. As I mentioned, we're talking with BRCA mutation carriers to determine how best to communicate personalized risk information.

To start things out, I would like to ask you a few questions about your experiences with cancer and genetic testing, and your thoughts about your risk for cancer. Please feel free to stop me and ask questions anytime and remember that you can skip any question.

1. How long ago were you tested for the BRCA 1/2 mutation?

2. Have you had cancer? Are you currently undergoing treatment?

3. Do you remember what the genetic counselor estimated your risk for cancer to be when you first got your genetic testing results? Do you remember your initial reactions to that estimate?

4. Do you feel like you have a good understanding of your cancer risk?

5. How susceptible to cancer/another cancer do you feel on a scale of 1-100? Why?

6. Do you feel like you are more or less at risk than women *without* a BRCA mutation? Why?

7. Do you feel like you are more or less at risk than *other* BRCA mutation carriers? Why?

8. How do you think have you "adjusted" to your cancer risk over time?

9. What kinds of things have you done to help reduce your cancer risk? Are you doing things now that you weren't doing before you went through genetic testing?

10. Do you worry about cancer?

Part 2: Risk Communication Preferences

As I mentioned to you at the beginning, the goal of this research is determine how best to communicate refined cancer risk estimates to women with BRCA mutation. To better understand your preferences, I'd like to hear your responses to a few sample scenarios.

1. Let's say a genetic counselor told you the BRCA mutation carriers have a 50-85% risk of developing breast cancer by age 80. If your genetic counselor could refine that percentage even further just for you, based on your age and variations in your DNA, would you be interested in that number? Why or Why not?

    a. Let's say that the counselor tells you that you (personally) have an 85-95% risk of developing breast cancer by age 80, which is 10% higher than BRCA mutation carriers your age. Would that information be useful to you? How do you think that information might impact your decision-making?

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b. Now, imagine that the counselor told you that your personal risk of developing breast cancer was much LOWER than BRCA mutation carriers your age (say 30-40% risk versus 50-85%). How might you respond to that information? Do you think that information might that information impact your decision-making?

c. But, what if that difference was only *marginally* LOWER (say your risk was 55-65% vs 50-85%)?

d. Do you like being presented with risk estimates as a range (like 50-85%) or would you prefer a specific percentage (say 88%)? Why or Why not? Would it matter the size of the range (i.e., a smaller versus a larger range)?

e. Would you prefer to be presented with an estimate of your *full* lifetime risk (from birth to age 80) OR would you prefer an estimate of your *remaining* lifetime risk (from now until age 80)? Would you prefer an estimate to age 80 or should we go higher?

   [ask only if they are currently cancer free] What if that estimate was conditional on you being cancer-free by a certain age?

I would now like to hear your thoughts about the best way to present this risk information.

1. If I were going to give you an estimate of your breast cancer risk between now and age 80, would you prefer that I did so using words like "you have a high or low risk of breast cancer"? Or, would you prefer that I used numbers like "you have a 50-85% risk of breast cancer." Why?

2. Next, I'm interested to know what you think would be the best way to communicate numerical information. Let's pretend a genetic counselor was going to tell you your risk of breast cancer.

   Taking a look at this list, would you prefer that the risk be presented as (1) a percentage, (2) a proportion or (3) in comparison to the general population?

   a) Why? Which of these formats do you think is the easiest to understand?

3. What if the genetic counselor added some *additional* information to the information you just saw. Take a minute to look at this figure and tell me what you think.

   a) What is different about this information from what you saw before?
   b) How might this additional information impact your perception of risk?
   c) Would you prefer this format or the one that I showed you a minute ago?

4. Now, let's say that a computer program could provide you with a more refined estimate of your breast cancer risk similar to what we talked about before. I want to show you two possible formats for how these estimates could be presented, to find out what you prefer.

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Here is the first format
Here is the second format

a) What is different about these two formats?
b) Do you think they are presenting the same or different information?
c) Do you have a strong preference for one format versus the other?

Now here is a third way to present this information
What is your reaction to this format? Does it help you better understand your risk relative to what I just showed you?

d) What if the computer program could ONLY tell your risk relative to other people? In other words, what if we couldn't provide you with the information in the first figure. Would you still be interested in the information?

5. Next, I am going to show you several figures to get your impressions of them.
   a) What is your understanding of this figure?
   b) What is your reaction to this figure?
   c) What do you like about this figure?
   d) What is confusing about this figure?
   e) What is your emotional response to the figure?

6. Of all the figures you just saw, which figure did you like best? Which figure was the easiest to understand? What changes would you suggest to that figure?

7. Now that you've seen all these different presentations of risk, let's talk about the information that was presented. What impact do you think this personalized risk information might have on BRCA mutation carriers? Do you think it could impact their decision-making about behaviors to reduce their risk?

8. Would having additional risk information that was personalized to your age and mutation status make you feel more or less in control of your cancer risk?

9. Who would you like to deliver this risk information? Do you think we could deliver the risk information, following initial genetic testing, using a computer or web-based program?
   Why or why not?

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