

Appendix 1. Survey and interview questions about motivations and concerns

Evaluation Method	Relevant Questions^a
Participation survey	<p data-bbox="483 275 1024 310">What are your reasons for joining this study?^b</p> <p data-bbox="483 338 1135 373">What concerns have you had about joining this study?^b</p> <p data-bbox="483 401 1325 459">This is a list of reasons other patients have given for joining studies like this one. Are any of these true for you? (Please check up to 3 reasons)</p> <ul data-bbox="483 464 1354 772" style="list-style-type: none"><input type="checkbox"/> I want to know my future risk for cancer<input type="checkbox"/> I want information that may help my family<input type="checkbox"/> I like to use the most up-to-date technology<input type="checkbox"/> Knowing my risk for genetic conditions may change my healthcare<input type="checkbox"/> Knowing my risk for genetic conditions may change how I take care of myself (e.g., diet and exercise)<input type="checkbox"/> My family encouraged me to join<input type="checkbox"/> My doctor encouraged me to join<input type="checkbox"/> I want to advance research <p data-bbox="483 804 1338 894">This is a list of concerns other patients have given about joining studies like this one. Do you have any of these concerns? (Please check up to 3 concerns)</p> <ul data-bbox="483 898 1354 1129" style="list-style-type: none"><input type="checkbox"/> It may be hard for me to do the things the study is asking me to do<input type="checkbox"/> I have concerns about my privacy<input type="checkbox"/> I am worried that my genetic test result may be used against me (e.g., by an employer, health insurance company, etc.)<input type="checkbox"/> I have concerns about participating in research<input type="checkbox"/> I am worried about how I will cope with the genetic information I will receive
Incompletion survey	<p data-bbox="483 1129 1110 1165">Please tell us why you decided not to join this study:^b</p> <p data-bbox="483 1192 1333 1283">This is a list from other patients who decided not to join studies like this one. Did any of these reasons affect your decision not to join this study? (Please choose up to three reasons)</p> <ul data-bbox="483 1314 1338 1556" style="list-style-type: none"><input type="checkbox"/> The things I need to do to be in the study didn't work well for me<input type="checkbox"/> I have concerns about my privacy<input type="checkbox"/> I am not interested in participating in research<input type="checkbox"/> My current health condition is all I want to focus on right now<input type="checkbox"/> I don't want genetic research results from this study<input type="checkbox"/> I'm worried about how I will cope with the genetic information I might receive
Consent interview	<p data-bbox="483 1556 1284 1623">How did you decide to join the study? (What made you interested in joining? What were you concerned about?)</p> <p data-bbox="483 1650 1138 1686">What was the most important reason for your decision?</p> <p data-bbox="483 1713 1312 1892">Now, I'd like you to think back to how you felt right after reading the information about the study. What were you feeling after reading the information? [Some people say reading this kind of information makes them feel anxious. Did you feel anxious? If so, what were you anxious about? How did you deal with your anxiety (look up information, talk to someone, etc.)?]</p>

What, if anything, concerned you about sharing your results when you read about that in the materials? How important were these concerns compared to what you hoped to get out of the study?

^a*The questions included here consist of those that pertain to motivations and concerns and were analyzed for this paper.*

^b*Open-ended survey questions*