Usability Testing and Understanding Genomic Uncertainty

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Abstract

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Abstract

Many cancers have a familial component that can be passed down to future generations and increase their risk of getting that cancer. Understanding one's family history of cancer can help that individual take preventative or prophylactic measures to decrease risk of cancer. A common way for medical providers to determine family history and cancer risk is through family health history collection surveys. These family health history collection surveys should be easy to use and have language that most reading levels can understand in order to get the most accurate results. Usability testing is one way to gain feedback on how well surveys and websites are understood by people at the average reading level. This study explored the opinions and views of participants who took a family health history collection survey and explored a website that served as a landing page for the survey.

In addition to usability, I assessed the role of uncertainty in genetic testing while evaluating reactions to the website. Genetic tests are available to evaluate many things about a person's ancestry and health, but it is unclear how the general public view the accuracy of such tests and what they expect to get out of genetic testing. This qualitative study used semi-structured interviews to learn about participants' experiences with genetic testing and how they plan or would plan, to use the results.

INTRODUCTION

The Utility of Family History Collection

Family health history collection has clinical and research utility. Family health history is a significant risk factor for many diseases, including cancer, as the risk of getting the disease increases when relatives have certain conditions[1]. Understanding the family history of the disease can expose genetic and nongenetic risk factors that researchers and clinicians can use to better understand the disease[1]. Clinicians with knowledge of a patient's family history can use specific prevention strategies to lower the patient's disease risk, consider prophylactic procedures, and implement screening practices in order to catch diseases early and provide appropriate care[1].

Genetic testing may be ordered by clinicians if a patient's family history indicates that they are at a higher risk for getting a heritable disease, such as cancer. The clinician can order a specific type of genetic test depending on the specific disease of concern. A clinician may want to look for a certain gene that increases the risk of disease, as possible to determine with targeted DNA sequencing, or may want to look at a panel of genes if there are many that contribute to a certain disease, such as with whole-exome sequencing[7].

Ensuring the Usability of Family History Collection Tools

Family health history collection is a useful tool for providers treating their patients. Because of its utility, there needs to be an effective and accurate method of understanding and collecting this information. There are many challenges to collecting family health history, such as lack of clinic time and patient preparation in provider settings[9]. However, there are other means of ensuring the patient is able to provide the better, more accurate information[2]. Family history collection tools that are simpler, and less time consuming have been shown to be the most accurate[3]. Family history tools that allow patients to collect and store family history at home, or over time, might give the most flexibility and support to patients recently diagnosed with life-threatening illness. Family history collection surveys are often conducted on a computer in which the results can be securely stored on the patient's electronic medical record, allow for easy access by the provider, and may allow for the patient to take the survey elsewhere than directly in-clinic[4].

Tools previously used in clinics have not been well adapted for primary care use, which has prevented many primary care facilities from adopting or implementing the tools[9]. Family history tools that can be self-administered by the patients have the most success with clinic implementation[9]. Family history tools that can be completed by the patients outside of clinic time will eliminate a barrier that prevents the adoption of these tools in clinics[9]. Patient directed improvements to family health history collection surveys will ensure that these surveys are as accurate as possible and ensure that most patients will be successful in understanding and completing the surveys [4]. Patients who underwent an online survey for their family health history noted several possible improvements for this survey that researchers had not considered previously, such as expanding the list of relatives, editing information, and the inclusion of other specific hereditary diseases[4].

Understanding Genetic Uncertainty in Primary Care Settings

Though patients are able to inform primary care physicians how to better collect family history, patients may not understand what their family history is able to tell them. Patients who have previously provided their concerns for genetic uncertainty were able to inform a framework of management strategies that can be helpful for other providers and patients in the future experiencing uncertain genetic results[5]. Patients with uncertain results have reported anxiety and distress about cancer risk, and concern about what an uncertain result means for their relatives[5]. Recording these types of responses and inputting them into a framework can inform future providers about their patients' needs and improve clinical response[5].

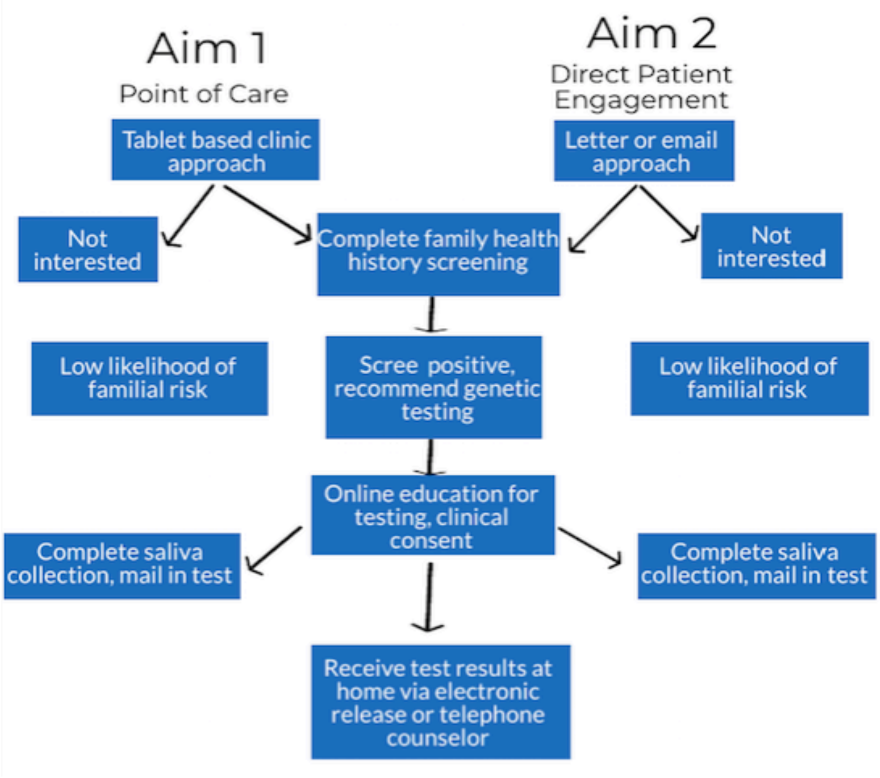
Though genetic testing has brought great advancements to the field of precision medicine, genomic testing introduces uncertainty at nearly every step of the testing process[6]. Much of the uncertainty comes from the reliability and accuracy of genetic testing, the sample acquisition, generating the results, and communicating the results to the patient[6]. Classifying genetic uncertainty will help providers and researchers establish expectations for their patients at every step of the testing process[6].

METHODS

The PICNIC Study

The PICNIC study aims to identify the best system to contact and screen patients from primary care clinics to potentially engage them in genetic testing. The PICNIC study will compare the efficacy of two strategies of reaching out to and obtaining screening of primary care patients and connecting those who are at higher risk of certain cancers to genetic testing. The PICNIC study has two study arms: Arm 1 is Point of Care in which patients will be approached in clinic of their primary care providers to complete the screening, or the family history collection survey; and Arm 2 which includes sending letters to patients of primary care clinics inviting them to complete the screening online. See Figure 1for flow for both arms.

Figure 1: PICNIC Study Flow

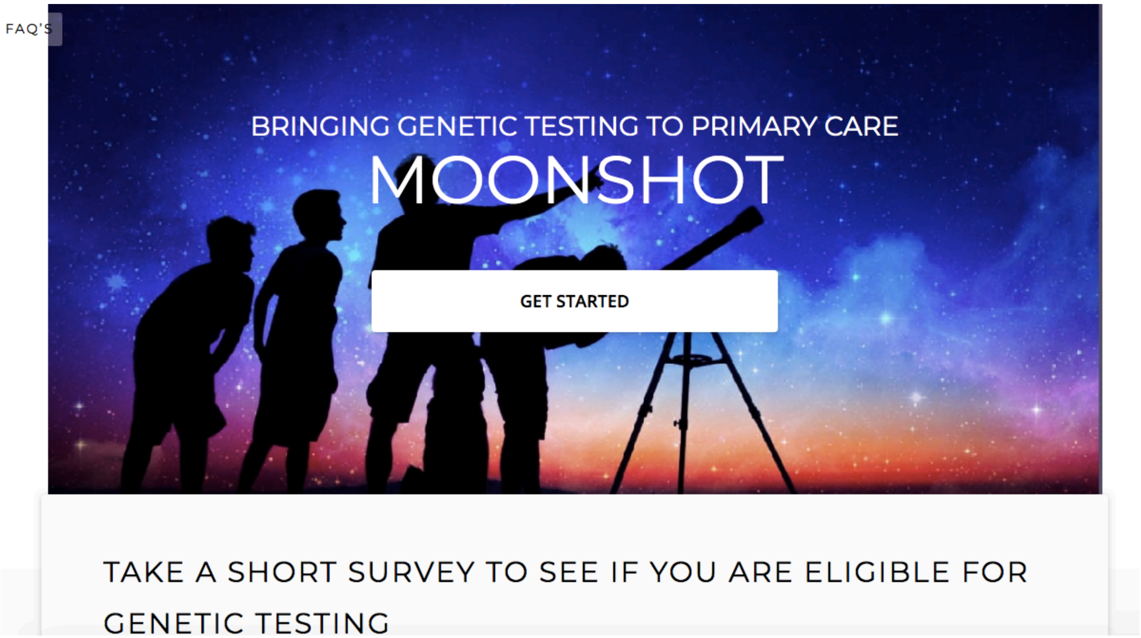


The patients of both study arms will be directed to the study's website, which will be the landing page to complete the family history collection survey. The website will include basic information about genetic testing, a study timeline, eligibility requirements, what they will be tested for if they do get genetic testing, and what their genetic testing results can tell them.

Development of Study Website and Survey

The PICNIC study's website was created with WordPress, using a template that allowed for the addition of buttons that allowed for quick re-direction to outside URL's, such as to RedCap for the family history survey. The website was intended to be eye-catching and professional to encourage patients to engage with the website and trust the validity of the study. See Figures 2 through 4 to view the webpage. The webpage included a "Get Started" button at the very beginning of the page, so that the patient can take the survey immediately, and another at the bottom of the page in case the patient was interested in learning more about the study. The FAQ page and survey was developed by members of the PICNIC study team.

Figure 2: Front page of the website.



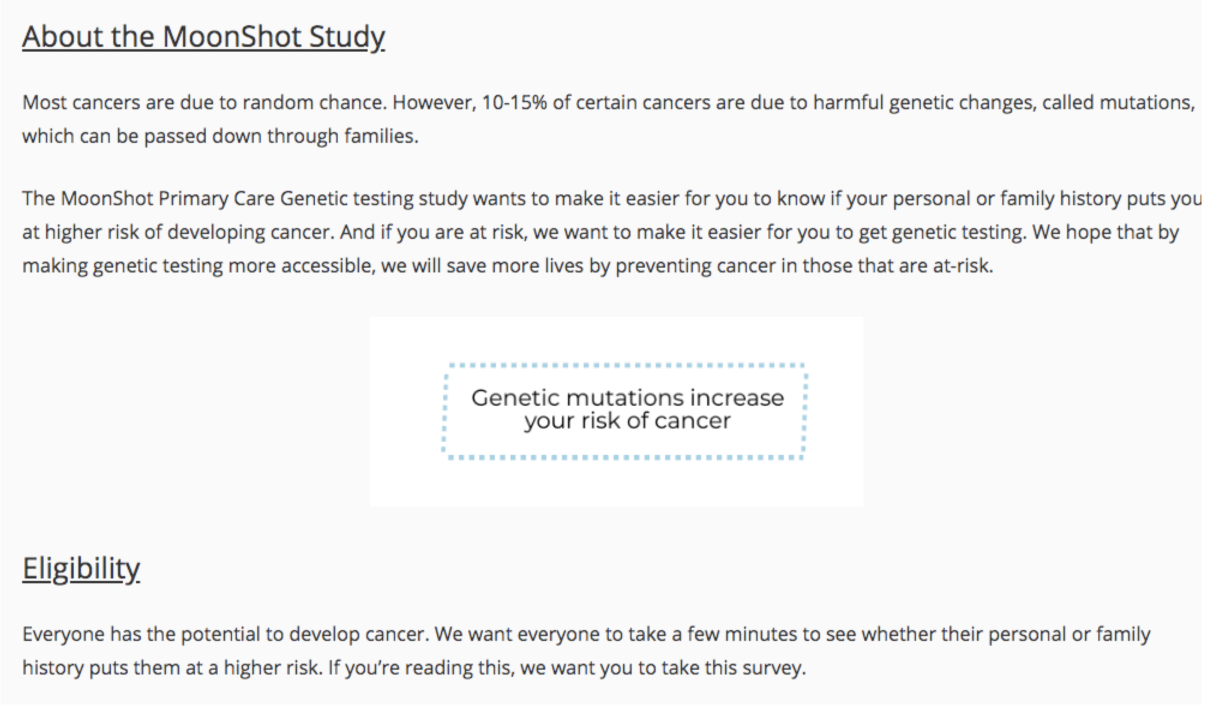
BRINGING GENETIC TESTING TO PRIMARY CARE

MOONSHOT

TAKE A SHORT SURVEY TO SEE IF YOU ARE ELIGIBLE FOR GENETIC TESTING

NOTE: MoonShot is the study name that will be used in clinical setting

Figure 3



About the MoonShot Study

Most cancers are due to random chance. However, 10-15% of certain cancers are due to harmful genetic changes, called mutations, which can be passed down through families.

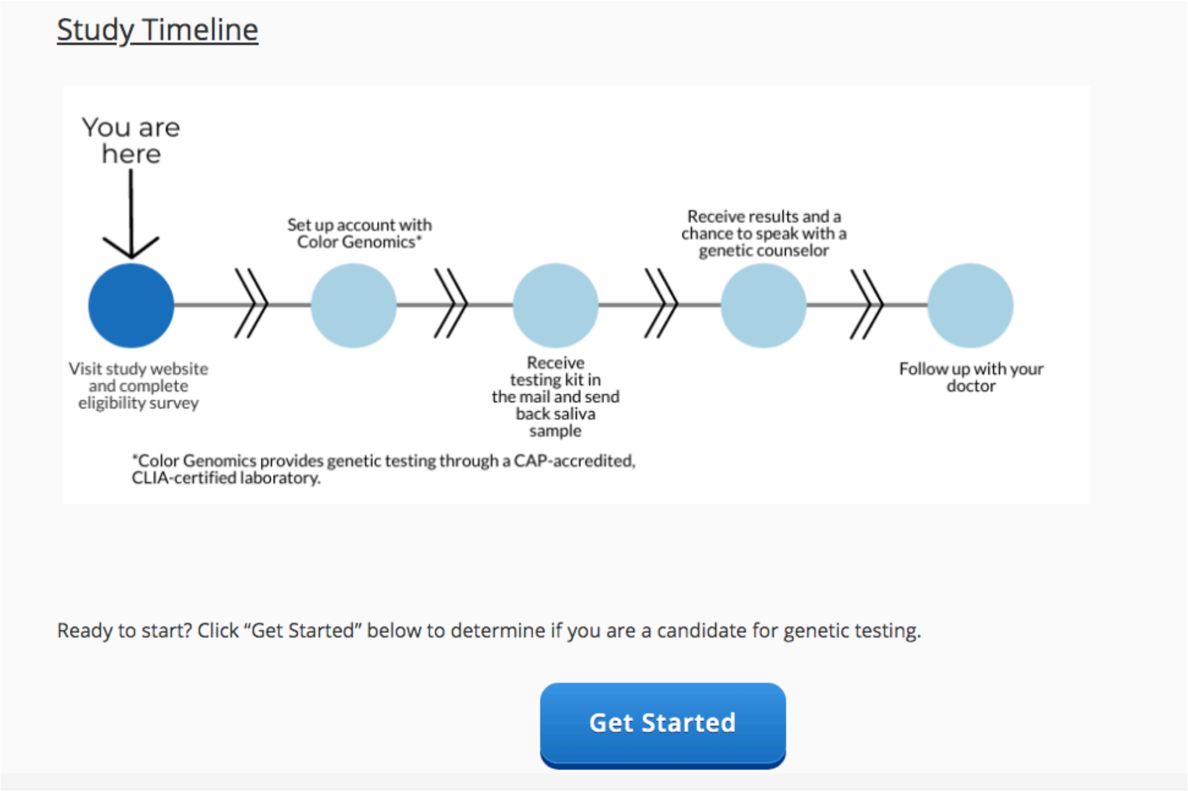
The MoonShot Primary Care Genetic testing study wants to make it easier for you to know if your personal or family history puts you at higher risk of developing cancer. And if you are at risk, we want to make it easier for you to get genetic testing. We hope that by making genetic testing more accessible, we will save more lives by preventing cancer in those that are at-risk.

Genetic mutations increase your risk of cancer

Eligibility

Everyone has the potential to develop cancer. We want everyone to take a few minutes to see whether their personal or family history puts them at a higher risk. If you're reading this, we want you to take this survey.

Figure 4



Study Timeline

*Color Genomics provides genetic testing through a CAP-accredited, CLIA-certified laboratory.

Ready to start? Click “Get Started” below to determine if you are a candidate for genetic testing.

Recruitment

For this project, I aimed to enroll between five to ten participants to be a part of both the usability testing and informal interview components of this study. To be considered eligible, participants needed to be 18 years of age or older and living in the United States. Participants were recruited via targeted paid ads and posts on Facebook. Those who were shown the ads by Facebook were algorithmically chosen as those users met the parameters provided by the researchers, which were the eligibility requirements. Those who were reached via Facebook were invited to message the study page directly or send an email to the study (see Appendix D). Those who reached out via Facebook messaging or email were responded to with a general email stating the purpose of the study, time expectations, and compensation. Those who were still interested in participating were invited to respond with their preferred device, whether or not they had video chat capabilities, and their chosen appointment date and time.

Think-Aloud

Prior to each participants' video chat appointment, they would be sent an additional email with the Zoom video chat link, the study's website URL, and two surveys. Once the participant was logged onto their Zoom appointment, I would read to them the study's expectations and their right to end the study at any time. Demographic information was collected from each participant at the start of the study in which I inquired about age, internet use, and preferred devices when using the internet. Audio and screen sharing were recorded with consent and they were then invited to begin the usability testing portion of the study.

Participants were asked to conduct three tasks related to usability of the website and survey. The first was to view the homepage of the website as they would in a natural, non-study setting. All participants felt compelled to read the entire webpage before clicking any buttons. Next, they were invited to view the FAQ page similarly to the home page. Participants were encouraged to use the Think-Aloud method as much as possible as they were viewing both webpages. Next, the participants were asked to click the "Get Started" button to be re-directed to the study's health history survey, called the hereditary cancer risk survey.

I asked the participant to begin sharing their screen and open the URL of the study's webpage. While viewing the website, they were asked to share their thoughts and opinions about the website as much as possible. I directed the participants to view the website as felt most natural and to describe what they were seeing and thinking. Each participant was given gentle prompts to encourage more discussion as they viewed the website. Once the participant felt that they had completed looking at the first page of the website, they were asked to click on the FAQ button where they would be redirected to the Frequently Asked Questions page. Similar to the previous page, they were directed to browse through the page as felt most natural to them if they were in a non-study setting. To encourage more open discussion and comments, participants were given gentle prompts and occasional probing questions to clarify ideas or concerns a participant may have.

I next encouraged the participants to click on the website's "Get Started" button once they felt they were ready to take the family history collection survey. The "Get Started" button would redirect them to the study's RedCap page with a family health history collection survey. The participants were directed to take the survey and answer the questions as honestly as possible.

Following the family health history survey, participants were asked to complete an additional survey that was adapted from Lewis' Post-Study Usability Study Questionnaire. This survey was a Likert scale in which the participants were given a statement about the website and family history survey, and then they would respond with their level of agreement with the statement. Participants could state that they either: strongly agreed, agreed, neither agreed nor disagreed, disagreed, or strongly disagreed with each statement about the website, survey, or system as a whole.

Post Usability Study Interview

This project also intended to learn more about the public's thoughts and feeling surrounding genetic testing, and their expectations regarding their results. Following the post-study survey, participants were invited to participate in an additional conversation regarding genetic testing. All six of the study participants agreed to participate in the interview. The interview was semi-structured, allowing participants to share whatever they wanted to about genetic testing. Participants' interview questions depended on whether or not they had any previous experience getting genetic testing. Those who had genetic testing done before received questions inquiring of the type of genetic testing, i.e. ancestral at-home DNA test or medical DNA sequencing, what led their decisions to genetic testing, and what they plan to do, or have done, with their results. Those who had not had any genetic testing done were given questions regarding their expectations regarding testing, what has kept them from getting tested, and what they would do with their results if they received testing in the future.

Data Analysis

Audio transcripts for each interview were extracted from Zoom, which has software that is able to provide written transcripts of audio recordings. Interview transcripts were first de-identified with participant numbers and had other identifying information redacted. Next each transcript was analyzed and coded by a single primary coder by hand and in sections, separating the think-aloud portion and the post testing interview. The coding framework for the think-aloud portion consisted of ease, usefulness, quality, and satisfaction. See Table 1 for codes and definitions. After applying these codes to each think-aloud portion from each participants' transcript, the transcripts were analyzed again to develop *a posteriori* codes in order to further capture all views and opinions of the website and survey. Following this set of coding, the responses from the Lewis Post Usability Questionnaire were given a numerical value between 1-5, with 1 considered the worse ranking and 5 the best. Then the responses to were calculated to determine the average score for each question. Finally, the post usability study interviews were also initially analyzed with *a priori* coding framework including cost, medical, family, uncertainty, see Table 2 for each code's definition. Each transcript was analyzed using these codes, then were evaluated again to develop a posteriori codes to ensure all sentiments and attitudes towards genetic testing were being included in the assessment. Finally, the codes for each section were reviewed in search of themes that emerged from the think-aloud portion and the post usability interview portion.

Table 1: *a priori* Codes and Definitions for Think-Aloud

Code	**Definition**
Ease	How straightforward and simple to website and survey is the use.
Usefulness	How helpful is the website in understanding genetic testing, and how helpful the survey is in providing family health history.
Quality	The standard or condition of the website and survey.
Satisfaction	The approval and liking of the website and survey

Table 2: *a priori* codes and definitions for Post Usability Interview

Code	**Definition**
Cost	Statements regarding payment for genetic testing
Medical	Comments referencing preventative measures, pharmaceuticals, health, or healthcare team
Family	Mention of familial relationships, or ancestry
Uncertainty	Ambiguity, anxiety, confusion surrounding genetic testing

RESULTS

Participant characteristics

A total of six participants were recruited using paid Facebook ads and posts, meeting the initial goal of recruiting five to ten participants. All interviews were conducted using Zoom and ranged in length from 30 to 55 minutes. The participants were all female, with an average age of the participants 28.3

years old, with an age range from 19 to 38 years of age. All participants used the internet daily and at least several times per day. Most participants were having the interview on their laptops, but most stated that their preferred device for internet use was their cell phones, unless they were using "more complex websites". No participant had a previous history of cancer.

Post Study Considerations

After the hereditary cancer risk survey had been completed, the participants were asked to complete and additional survey, the Lewis Post-Study Usability Questionnaire. The responses to each statement were given numerical values to better calculate the scoring of usability. Strongly agree was given the value of 5; agree the value of 4; neither agree nor disagree the value of 3; disagree the value of 2; and strongly disagree the value of 1. The participants were given statements that were about either the just the website, the system, which included the website and survey combined. Table 3 contains the average numerical score for each statement given in the Post Study Questionnaire.

Table 3 Likert Scale Scoring

Statement	Average score, numerically
The website was easy to use	4.2
I understand how to operate the website	3.8
Learning how to operate the website is easy	4.2
I could effectively complete the tasks and scenarios using this website	4.2
I was able to complete the tasks and scenarios quickly using this system	4.4
I felt comfortable using this website	4.2
Whenever I made a mistake, I could recover easily and quickly	4.2

The information provided with this website was clear	3.8
The information provided by the system is easily understood	4.2
The information provided by the website helps me to complete the task effectively	3.4
Using the system interface is enjoyable	3.8
The interface of this system was pleasant	4.4
It was easy to find the information I needed	3.6
The website has all the functions and capabilities I expected to have	3.8
I am satisfied with the overall system	3.8

Two statements from the Post Study Questionnaire had considerably lower rankings than the others: “The information provided by the website helps me to complete the task effectively” with a score of 3.4 and “It was easy to find the information I needed” with score of 3.6. These scores may best be addressed by comments such as, “I don’t know how private my data will be…I’m nervous to take a survey if I don’t know my data is being taken care of.” and “I’m not sure if this is a complementary test or not, I would want to know that before we “Got Started”.” Privacy and cost were common concerns that came up during the think-aloud portion, and may be a barrier that would prevent future participants from moving forward with the screening. Participants who expressed concerns over data privacy and cost of testing suggested I include this information on the front page. Another participant pointed out that she would feel confused about what to do if she did have a genetic mutation after looking at the website, she felt that there could be more information about next steps and whether or not the genetic information would go to her doctor.

Content Analysis of Think-Aloud

After a content analysis of the transcripts from the think- aloud portion of the project, major themes had emerged: aesthetics and barriers. Participants all had varying views on the overall look of the website. Many participants commented positively of the main picture of the website, others felt it was confusing as it was a picture related to space and not genetics. Some participants also commented on the order of the tagline and the site's title. Many participants noted the "clean look" of the website, and they viewed it as "professional". One participant noted that quality of the pictures was lacking, that they looked slightly blurry on her laptop screen.

Participants were able to point out barriers to understanding the purpose of the website or the study in general. Some participants requested more information to be added to the home webpage to disclose the study is mostly about hereditary cancer risk, not all cancer risk. Other participants noted that they felt they would be overwhelmed if more information were to be added, as they are lay people in genetics and don't want to overwhelmed with complicated genetic information.

Informal Interviews

Content analysis was conducted over the informal interview transcripts and codes that had been developed *a posteriori* were reviewed for overarching themes from all of the participants. Themes and corresponding definition and content codes are displayed on Table 4:

Table 4: Emerging Themes, *a priori* codes in bold

Theme	Definition	Content Codes
Barriers	What keeps people from obtaining genetic testing	**Cost**, age, privacy concerns, fear, insurance, **uncertainty**, discrimination, passing on genes

Behaviors	Actions directly related to getting testing or receiving results	Information seeking, resources, education, **family**
Health	Role genetic testing has on health of self and generations	Prevention, **medical**, sharing results, risk, lifestyle changes

Barriers

Participants who had not previously had genetic testing cited cost as a barrier to genetic testing. These participants felt that genetic testing may be something that they would be interested in having, but the cost and not understanding how it is covered through insurance prevents them from pursuing it. One participant explained that she would like to get genetic testing done through a doctor's office but "it's hard to get that covered by insurance unless you know that you have a hereditary mutation… that is really bad".

Two participants also discussed how they felt giving out their genetic information to third party companies prevented them from getting genetic testing. According to one participant,

> "I know that HIPAA protects patients, but [private companies] are kind of a gray area. They are not necessarily doctors… so what do they do with all of my data?"

One participant explained that she would be worried about how her life would be affected if her genetic results became public. She wondered, "could I lose my job or be denied insurance?".

Participants had other fears when it came to genetic testing. Many participants stated that they would be worried about what they would find out about genetic testing. One participant stated that she would feel "doomed" if she found out she was a higher risk of cancer. Many participants felt anxiety at the thought of passing on harmful genes to their children. Other participants were concerned about genetic discrimination from their insurance companies, or even from their friends and family.

> "[If my genetic testing results] was something that had to do more like psychiatric stuff. I probably would keep it to myself, with the difference being of more of a social perception".

Behaviors

Nearly half of the participants felt that there were specific behaviors that would be required of them once they received testing or their results. They felt that they would have to find resources on their own to stay up to date on genetic research or to learn more about what their genetic results mean. Some participants noted that their primary care doctor may be a good source to stay up to date on their genetic information, but one participant felt that she felt that she would need to find a new provider as she would want "a strong healthcare team to support me with my [genetic] results". Notably, only one participant had genetic testing done to better bond with family members. This participant wanted to encourage all family members to get genetic/ancestral DNA testing done so that they could all better understand where they had come from, especially since they had lost patriarchal members of their family. This participant felt they could research and potentially visit where they had had come from.

Health

All participants except one, who found genetic testing as more of an exploration of ancestry, noted what an impact genetic testing would have, or have had, on their health and health behaviors. Preventative measures were brought up several times by participants who felt genetic testing could have a positive impact on their lives, even if they received less than ideal results. Many participants noted that they would take results that displayed a higher risk of cancer as a sign that they would need to get frequent cancer screenings at earlier ages. Some felt that they may adjust their diet and exercise plans if they learned that they had a higher risk of cancer. One participant explained that she may feel compelled to completely cut sugar out of her life, depending on her genetic results. She said. "diabetes runs in my family. If I knew I had a gene that would give me diabetes, I would quit eating sugar to prevent it".

Discussion

Application of the think-aloud

After the think-aloud portion this study, I found that most participants were mostly pleased with the website and survey. The participants appreciated the clean copy and the flow in which information was laid out. Conducting think-aloud's and collecting participants' opinions with a questionnaire will help guide the future direction of the website and health history survey. Getting the direct views of the participants as they first viewed the website and as they learned from it in real-time gives insight as to how the website can be updated to get the desired responses. One of this study's primary goals is to acquire patients' comfort and trust so they can feel they can safe and easily participate in the screening and genetic testing, and all website updates will be targeted towards participant responses that challenged these goals.

Exploring the views surrounding genetic uncertainty

The participants seemed to understand the utility of receiving genetic results, as nearly all of them pointed out health behaviors they can change if they were found to have a higher risk of cancer. However, these participants discussed changing health behaviors hypothetically and only after they were to discover a hereditary cancer gene. No one had discussed that they potentially always are at risk of some type of cancer, and that they could be applying these healthier behaviors and lifestyle changes at anytime. Previous literature indicates that an individual's true cancer risk is often at odds with their perceived risk of cancer, depending on perceived family history of cancer[10]. Sociological researchers believe that the genetics field models cancer risk in "static, objective terms, instead of providing a livable framework that can reduce everyone's risk of cancer, no matter their true risk [10].

Participants discussed the assumed unattainability of genetic testing. I knew from the literature that most people believe that cost is a primary concern, but a common idea that repeatedly came up was the belief that they would have to either potentially forgo the privacy of their genetic data and get genetic testing done through a third party company, or risk an insurance denial and pay hefty out of pocket costs for genetic testing. However, an individual's willingness to pay will often change based on their perception of cancer risk[11].Those with higher cancer worry will usually be willing to take on any debt necessary to understand their disease, or disease risk, and no participant expressed any concern of having a higher than usual cancer risk[11].

Limitations

There were many limitations to this thesis project. Every participant was under 40 years of age and were all female. A more diverse study population could have different views on the ease of website use. All participants were recruited via internet and claimed to use the internet daily, so participants already had a familiarity with internet and computers. There also was limited variability of devices as most participants were using laptops, although at least one used an iPhone and one used a tablet. Also, no one in the study had a history of cancer, so their views of the survey and website may differ than those who may look at genetic testing in a more familiar way.

Conclusion

This study was successful in learning about opportunities to improve the website to make it more accessible and understandable. More changes may need to be considered in the future once a broader audience is reached. As pointed out in the limitations, those who took part in the think-aloud are younger and have more experience and comfortability with computers and websites. It was also interesting to gain insight from arguably young, healthy women about genetic testing, and the role they see it playing in their lives. Most seemed to understand that genetic testing was intended to provide cancer risk, not give an absolute diagnosis of cancer.

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Appendix

Screening/Demographic Questions

I will be recording your answer to these questions in writing. You are free to opt out of answering any of these questions as we go on. Most may be answered with a yes or no question.

What is your date of birth?

____ / _____/ _______

MO DAY YEAR

A IF UNDER 18 YEARS OLD: I’m sorry, but we’re only interviewing people over 18 years old, at this time. Thank you for your time. Good bye.

Do you use the Internet or email, at least occasionally?

About how often do you use the Internet?

o Almost Constantly
o Several times a day
o About once a day
o Several times a week
o Less often
o I don’t know
o No answer

Do you access the Internet from a cell phone, tablet, or other handheld device, at least occasionally?

What type of device are you using today?

What is your preferred device?

Appendix C
Usability Test Script

Now that we have completed our initial screening questions, I will be walking you through today's session.

Before we begin, I'm going to tell you a little bit more about the study so you know what to expect. I'm going to read it to make sure I cover everything. I can answer any questions you may have about the study.

We're asking people to go through our website and survey. We will be asking research participants to proceed through the website to enroll in a study. Our goal of running this usability test is to see if the website chain works like it's intended. At the end, you will also be asked to participate in a discussion with me about genetic testing. Today's session should take about an hour in total.

The first thing I want to emphasize is that we are testing the websites, not you. You can't do anything wrong here.

As you explore the website, I'm going to ask you to think out loud as much as possible. I would like you to tell me about what you are looking at, what you are trying to do, and what you are thinking. If anything doesn't make sense with the website, tell me. If something is unclear, or if you can think of a better way to do something, tell me. Anything you notice in terms of function, appearance, or anything else, please share it out loud. This will be a big help to us, and assist us in figuring out where improvement is needed.

Also, don't worry about hurting my feelings. We're doing this to improve the website, so we really need to hear your honest reactions.

If at any time you have a question, just ask. I may not be able to answer you right away, since we're interested in how people do when they don't have someone to help them. But if you still have any questions when we're done, I'll try to answer them at that time. And if you need to take a break at any point, just let me know.

Do you have any questions? If you don't have any questions, I'm going to ask you to tell me briefly, using your own words, what the purpose of this study today is about?

Give participant an opportunity to ask any questions and explain the study back to the researcher, in their own words.
Do you have any questions so far?
Okay, great. Now we can start looking at the websites.
Request the participant to open the link to the MoonShot webpage. This link should be included in the webchat invitation, or we can resend to their email.

SHARE SCREEN

First, I’m going to ask you to look at this page and tell me what you make of it.

Prompts to encourage participants to explore different features of the page:

- What strikes you about it?
- Whose site do you think it is?
- What can you do here?
- What do you think this page is for?
- Just look around and do a little narrative.

You can scroll if you want to, but don’t click on anything yet.
And again, as much as possible, it will help us if you can try to think out load so we know what you’re thinking about.

OPEN link for hereditary cancer
Go ahead and answer the questions as honestly as you can. If you have any questions or notice anything that may be improved, please let me know
Allow the participant to proceed with the Cancer Risk Survey on RedCap. If they seem stuck, provide gentle prompting such as, “talk to me about what you are thinking”.

When the participant has completed usability testing protocol, they will be directed to an additional survey.

We are wrapped up with the actual website work. Next, I’m going to ask you to complete a very brief survey about your experience. This should take less than ten minutes to complete, at which point I will ask that you participate in the genetic testing discussion.

Appendix E

Thank you again for choosing to have this discussion with me. I want to let you know that this is completely voluntary and you have the right to stop the interview at any time and to not answer any question you aren't comfortable with. For this section, I am just wanting to learn more about what you think about genetic testing. This should take about 30 minutes. Do you have any questions before I begin?

Have you ever had genetic testing done before?

If yes:

Where did you receive genetic testing (ie at a doctor's office or a home testing kit?)

What drove your decision to have genetic testing done?

How did you feel after you received your results?

Have you ever used your results to help make a medical decision?
  Or, do you think you will in the future?

Have you encouraged other family members to get genetic testing done based off of your results?

Have you ever shared your results with family members?

If you had home testing done, did you share your results with your provider?
  What was that experience like?

Have you ever checked in with your provider about reclassification or uncertain results?

What resources would you use if you wanted to learn more or stay up to date on research on genetic testing?

If no:

Have you thought about getting genetic testing done before?
  Why or why not?

What reason, if any, has kept you from getting genetic testing?

Has anyone in your family had genetic testing done that you know of?

What do you think you'll learn from genetic testing?

Do you have any concerns about what your genetic test results will tell you? Specifically, what are they?

How do you think you will use your genetic testing results in the future?

Will you consider your genetic testing results before making medical decisions?

Do you think you'll share your results with anyone in your family?

Will you try to learn more about your results over time? If so, what resources will you use to learn about them?

Thank you for taking the time to talk with me about genetic testing. Your input has been very helpful to our study.

Appendix D

Hello,

Thank you for considering being a part of the MoonShot study! My name is Kelly and I am working on this study that is being conducted at the University of Washington. Our study is testing out a website and survey that will be used to recruit participants for a larger research study.

Being a part of this study would require an online video chat on a date and time of your choosing. During this chat, we will ask that you participate in a brief, approximately 30 minute, usability test (see more details about this below). After the usability testing is finished, we will ask you to participate in an optional, informal conversation about your thoughts on genetic testing. You will be provided with a (gift card and amount) for your time in conducting this study.

Prior to beginning the usability test, we will walk you through the study and study procedures again, and address any questions you may have. During the usability test, we will ask you interact with a website on a tablet, and tell us what you think about the webpages. I want to emphasize, that we are not testing your ability to use the webpages. Our focus is on exploring how user-friendly this website is. We will ask you to tell us what you like and what needs improvement. These usability tests will be tape recorded and stored in a secure location. Your name will not be attached to these files.

There is no expected potential for injury related to this research project. We would also like you to know that your participation in this study is completely voluntary. You are free not to participate or to withdraw at any time, for whatever reason. We will not collect any personally identifiable information that would link you to participating in this research study.

If you would like to participate, I would ask that you reply to this message with your email address, whether or not you have a Zoom, Skype, or Google account, and your preferred type of electronic device (such as a smart phone, tablet, desktop, or laptop).

Thank you again for your interest,

The MoonShot Study