March 2023

Piloting a Spanish-language Web-based Tool for Hereditary Cancer Genetic Testing

Gretter Manso

University of South Florida

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Piloting a Spanish-language Web-based Tool for Hereditary Cancer Genetic Testing

by

Gretter Manso

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science with a concentration in Genetic Counseling College of Public Health University of South Florida

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Date of Approval:
March 9, 2023

Keywords: genetic counseling, cancer, education, public health

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Abstract

Cancer genetic services (including genetic counseling and testing) help identify patients and families at increased risk of developing cancer so that steps can be taken to reduce risks or find cancers early. Receipt of genetic services in the Hispanic/Latinx population is low due, in part, to a shortage of Spanish-speaking genetic counselors. To address this concern, a 12-minute online tool designed to inform individuals about cancer genetic services was translated into Spanish. The objectives of this pilot study were to determine if the educational tool improves knowledge and informed decision making and to assess usability and appropriateness of the tool in the Hispanic/Latinx population. Individuals with a personal or family history of cancer were recruited at a Cancer Center in Puerto Rico as well as through social media and 41 completed a survey before and after viewing the tool. Additionally, 10 select participants completed a semi-structured interview in Spanish. Paired t-tests and Cohen’s d were calculated to assess for changes in knowledge and informed decision making. Interview transcripts were translated from Spanish to English and inductively coded and analyzed. Participants showed large increases in both knowledge scores (p<.001, d=0.56) and feelings of being informed and empowered to decide about getting genetic testing (p<.001, d=0.91). Despite significant improvements, 49% of participants did not feel fully informed and empowered after viewing the tool. Although participants found the tool aesthetically pleasing and easy to use with informative and valuable content, they also made recommendations for general improvement to be applied in future iterations. In addition, while some participants expressed understanding of topics covered in the tool, there were some who were still unclear. Results suggest this Spanish-language tool is user-
friendly and appropriate at informing and empowering many individuals to decide about cancer genetic testing. However, individuals who are not fully informed and empowered after reviewing the tool may benefit from genetic counseling prior to testing.
Chapter 1: Introduction

Hispanics/Latinx compromise more than 18% of the U.S. population, making them the largest minority group. Cancer is considered the leading cause of death in this population (CDC Wonder, 2020). Hereditary cancer genetic testing services are valuable in identifying patients and their families who may be at an increased risk of developing cancer. When a patient is identified to have a hereditary predisposition to cancer, they are offered high risk surveillance and management options that can reduce cancer morbidity or mortality (Nelson et. al, 2014).

Among the Hispanic/Latinx population in the United States, uptake of genetic testing services for hereditary cancers is low (Canedo et. al, 2020). There are a multitude of barriers affecting access to these services. One of these barriers is ineffective information-giving during a genetic counseling session stemming from the provision of unnecessary information, use of complex terminology by the genetic counselor along with the patient perceiving the information to be irrelevant for themselves and/or their families (Joseph et. al, 2017). In addition, Hispanics/Latinx individuals face limited availability and inadequate interpreter services and problems with verbal and written communication during visits (Hamilton et. al, 2019). Moreover, only a small number of genetic counselors provide services in Spanish which currently does not meet the needs of the Hispanic/Latinx patient population seeking genetic testing (Augusto et. al, 2019). Although there is a low awareness of genetic testing services, there is still a desire to learn more about these services by the Hispanic/Latinx population (Dron et. al, 2022).

To address these barriers and increase access to genetic testing services, use of online educational tools have been proposed to supplement the information-giving portion or the pretest
counseling portion of the genetic counseling session (Cohen et. al, 2016). Previously, it was found that Hispanic/Latinx individuals preferred visual aids that were colorful and contained pictures of people who looked like them as well as content that was simple and relevant (Kinney et. al, 2010). Interestingly, research by Samuel et. al (2017) suggests that in providing informed consent, information may not be as important to patients “in relation to other emotional, social and/or personal concerns and therefore they may have less need or desire to understand it” (p.8). This research proposes it may be more fruitful for genetic counselors to focus on the psychosocial needs of their patients instead of devoting most of the time to providing patients with information in a genetic counseling session.

Based on the available literature, the impact of a web-based Spanish-educational tool designed to support informed consent for Hispanic/Latinx patients in lieu of cancer pre-test genetic counseling has not been evaluated. However, a similar English version of this tool has been shown to significantly increase knowledge across different health literacy levels and increase the number of individuals who felt both informed and empowered to decide about genetic testing (Cragun et. al, 2020). We aim to determine whether the Spanish version of the tool is effective at providing the knowledge necessary for individuals to feel informed and empowered about genetic testing for hereditary cancers and to evaluate the usability and appropriateness of the tool among Spanish speaking individuals.
Chapter 2: Methods

This study was approved by the University of South Florida Institutional Review Board (IRB) and all participants consented via a Spanish language consent form. The study was approved as continuation of a previous USF thesis project (Alastre, 2021). Procedures followed the ethical guidelines laid out in the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.

Spanish-language Tool

A 12-minute web-based tool designed to inform individuals about cancer genetic services was adapted and translated into Spanish (Cragun et. al, 2020). The tool was animated and designed to cover educational aspects of a hereditary cancer genetic counseling pre-test session. The content of the tool, including its graphics and script, was adapted for the Hispanic/Latinx population based on input from a practicing genetic counselor and a genetic counseling student who were both Native Spanish speakers. The main content takes about 12 minutes to view, but individuals are allowed as much time as they would like to click on the “learn more” buttons which contain additional detail that developers of the English tool had agreed was unnecessary for informed consent.

Participant Recruitment and Data Collection

The inclusion criteria consisted of Spanish-speaking individuals living in the U.S states or territories who are 18 years or older, whose preferred language(s) for receiving health information is Spanish or both English and Spanish, and who have a personal and/or family
history of any type of cancer. Participants seen at the Cancer Center in Puerto Rico in fall of 2022, were given a flyer inviting them to participate in this study before their visit with their oncologist or surgeon. In addition, some participants were recruited through a post on Facebook, Instagram, and WhatsApp. The flyers contained an email address and/or link that allowed the participants to learn more information about the study. People who met the study criteria and were instructed to review the Spanish informed consent form. The pre-tool survey took approximately 5-to-10 minutes to complete online. Once the pre-tool survey was completed, a link led to the educational tool. Once participants viewed the educational tool, a final link took them to complete the post-tool survey. Participants who failed to complete all aspects of both surveys were excluded from the study.

All participants who indicated on the post-survey that they would be willing to be interviewed were contacted to set up a convenient time to give additional information about the tool. Participants who responded and agreed to meet were interviewed. Interviews were conducted in Spanish and recorded via Microsoft Teams. Participants who completed an interview were given a $20 Amazon or Walmart electronic gift-card. Prior to completing the interview, participants provided verbal consent to record. No personal health information was requested during the interview.

**Pre- and Post- tool Surveys**

The pre-tool survey contained basic demographic questions and both the pre- and post-tool surveys contained some questions to assess hereditary cancer genetic testing knowledge, extent to which they felt feeling informed and empowered to decide about genetic testing, and attitudes/interest in genetic testing. A 5-point Likert question “How often do you have problems learning about a medical condition because of difficulty learning written information?” was
included in the pre-tool survey as a proxy for health literacy. Based on their answer, health literacy levels were assumed which ranged from low, low-medium, medium, medium-high, and high. The post-tool survey contained a few free response questions where participants could provide written feedback on the educational tool and a question asking participants if they would like to volunteer to provide additional feedback on the educational tool. The pre and post tool surveys were adapted from a previous thesis project (Alastre, 2021).

General genetic testing knowledge was assessed using 9 questions covering several elements discussed throughout the tool including inheritance, usability of genetic test results, limitations of genetic testing, and laws in place to protect an individual’s genetic testing information. The possible response options were “agree”, “disagree”, and “don’t know.” Each correct response received 1 point for a maximum total of 9 points.

Feelings of being informed and empowered to decide about genetic testing was assessed though the SURE measure consisting of 4 questions that measured the following: Sure of myself, Understand information, Risk-benefit, and Encouragement (Legare et. al, 2010). Possible answers included “yes,” “no,” and “don’t know.” One point is assigned for each question to which the participants responded “yes,” creating a total score with a theoretical range from 0 to 4. Participants who answered “yes” to all 4 questions are deemed to be fully informed and empowered to decide about genetic testing.

Attitudes about genetic testing were evaluated using 3, 5-point Likert-style questions assessing if the participants find genetic testing useful, if obtaining genetic testing is important for themselves, and if they would like to obtain genetic testing. The average of each participant’s score was calculated, with a higher number indicating a more positive attitude toward genetic testing.
The post-tool survey also contained a few free response questions where participants could provide written feedback on the educational tool and a question asking participants if they would like to volunteer for an interview to provide additional feedback on the educational tool.

Interview Guide

The semi-structured interview guide was created in English and translated into Spanish by a genetic counseling student and back-translated into English by a genetic counselor, both of whom are fluent in Spanish. Questions assessed the participants’ opinion about the tool’s visual aesthetics, audio quality, particular aspects of the slides presented, what they liked, and recommendations for improvement. In addition, the questions also assessed how they would feel if they were to get each of the three possible genetic test results (positive, negative, Variant of Uncertain Significance [VUS]). For reference, a positive test result on a genetic test means a pathogenic variant was identified that is known to increase the risks for cancer. A negative test result means there was no variant identified. A VUS test result means there was a variant identified but it is uncertain whether the variant increases cancer risk. A VUS result is not utilized to alter a patient’s care. Interviews were adaptative in nature, and additional probes about the tool were added based on the feedback that was received from the first few participants. Sonix AI transcription software was utilized to transcribe the interviews in Spanish. The PI, who is fluent in Spanish, and has some previous training and experience as a medical interpreter, translated the interviews. The interview guide was adapted from a previous thesis project (Alastre, 2021)

Quantitative Data Analysis

Data from the pre and post tool surveys were analyzed using SPSS Statistics (IBM corp, version 26). Paired samples t-test, Cohen’s d, and mean scores were calculated to assess for pre-post changes in knowledge scores, SURE measures, and
attitudes towards testing. Cohen’s d is a measure of effect size, where 0.2 is considered small, 0.5 medium, and greater than or equal to 8 as large (Sullivan & Feinn, 2012).

**Qualitative Data Analysis**

Qualitative data analysis of the interview transcripts was completed using Nvivo software. The PI coded translated interview responses into both categorized feedback and themes using Braun and Clarke’s method of thematic analysis (Braun & Clarke, 2006).
Chapter 3: Results

Quantitative

A total of 111 started the pre-tool survey and 41 fully completed both the pre- and post-tool surveys. Participant demographics are shown in Table 1. Most participants were female and Caribbean Islanders with a family history of cancer. Positive changes in pre- and post-tool mean knowledge scores were significant (Table 2) and a Cohen’s d of 0.56 indicates a medium effect size was obtained (Sullivan & Feinn, 2012). Only 15% of participants felt fully informed and empowered (i.e, a score of 4 on the SURE measure) before viewing the tool, which jumped to 51% after viewing the tool. Feelings of being informed and empowered increased significantly from pre-to post in Table 2 and a Cohen’s d of 0.91 indicates a large effect size was obtained (Sulliva & Feinn, 2012). The mean scores for attitudes towards genetic testing on a 5-point scale were 3.10 and 3.13 for the pre-and post-tool, respectively which showed no change (p=0.77).

Qualitative Feedback Related to the Tool

Of the 25 participants invited to be interviewed, 10 completed an interview and others were lost to follow-up. Feedback from the semi-structured interviews was categorized into four main categories. Each category was further broken into several subcategories shown in Table 3 alongside exemplar quotes. The aesthetics category was divided into visual quality, audio quality, and narrator’s voice. Overall participants found the tool to be visually pleasing and “dynamic”. One out of the ten interviewees commented they did not find the visuals attention-grabbing. Most of the participants mentioned the audio quality could be improved as there were
differences in volume throughout the tool however, most agreed the audio proceeded at an appropriate pace and the narrator’s voice was clear and understandable.

**Table 1. Participant demographics**

<table>
<thead>
<tr>
<th>Category</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>31 (75.6)</td>
</tr>
<tr>
<td>Male</td>
<td>10 (24.4)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>3 (7.3)</td>
</tr>
<tr>
<td>30-39</td>
<td>3 (7.3)</td>
</tr>
<tr>
<td>40-49</td>
<td>11 (26.8)</td>
</tr>
<tr>
<td>50-59</td>
<td>12 (29.3)</td>
</tr>
<tr>
<td>60-69</td>
<td>9 (22.0)</td>
</tr>
<tr>
<td>70-79</td>
<td>3 (7.3)</td>
</tr>
<tr>
<td><strong>Preferred language of med info</strong></td>
<td></td>
</tr>
<tr>
<td>Spanish</td>
<td>31 (75.6)</td>
</tr>
<tr>
<td>Both equally</td>
<td>10 (24.4)</td>
</tr>
<tr>
<td><strong>Clinical cancer history</strong></td>
<td></td>
</tr>
<tr>
<td>Never diagnosed</td>
<td>22 (53.7)</td>
</tr>
<tr>
<td>Previously diagnosed</td>
<td>4 (9.8)</td>
</tr>
<tr>
<td>Currently diagnosed</td>
<td>15 (36.6)</td>
</tr>
<tr>
<td><strong>Has a family history of cancer</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>38 (92.9)</td>
</tr>
<tr>
<td><strong>Genetic testing completed</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 (26.8)</td>
</tr>
<tr>
<td><strong>Family completed genetic testing</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 (26.8)</td>
</tr>
<tr>
<td>No</td>
<td>23 (56.1)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7 (17.1)</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Caribbean islander</td>
<td>35 (85.4)</td>
</tr>
<tr>
<td>South American</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td>North America (U.S./ Canada)</td>
<td>2 (4.9)</td>
</tr>
<tr>
<td>Central American</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
</tr>
<tr>
<td>High school not completed</td>
<td>2 (4.9)</td>
</tr>
<tr>
<td>High school completed</td>
<td>13 (31.7)</td>
</tr>
<tr>
<td>Some college</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td>College graduate</td>
<td>11 (26.8)</td>
</tr>
<tr>
<td>Postgraduate degree</td>
<td>14 (34.1)</td>
</tr>
<tr>
<td><strong>Health literacy</strong></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>14 (34.1)</td>
</tr>
<tr>
<td>Medium-high</td>
<td>13 (31.8)</td>
</tr>
<tr>
<td>Medium</td>
<td>14 (34.1)</td>
</tr>
</tbody>
</table>
Table 2. Results of paired samples t-tests showing changes in participant knowledge scores and feelings of being informed and empowered before and after viewing the tool

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>df</th>
<th>p</th>
<th>Cohen’s d</th>
<th>95% CI for Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge scores(^{a})</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>3.71</td>
<td>40</td>
<td>&lt;.001</td>
<td>0.56</td>
<td>0.89 0.23</td>
</tr>
<tr>
<td>After</td>
<td>5.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of being informed and empowered about GT(^{b})</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>1.76</td>
<td>40</td>
<td>&lt;.001</td>
<td>0.91</td>
<td>0.54 1.28</td>
</tr>
<tr>
<td>After</td>
<td>3.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^{a}\) Knowledge scores can range from 0 to 9

\(^{b}\) SURE measure scores can range from 0 to 4

The content category is divided into complexity of language, easy to understand, and value of information. Some participants found the tool to be simple despite the complex language involved however others thought some of the language could be difficult to understand for people who are exposed to this type of content for the first time. Overall, most participants expressed the tool was valuable to them based on the knowledge they gained both for themselves and for family members.

The comprehension category is further divided into understanding of hereditary cancer and cancer risk perception based on specific probing questions in the interview. When participants were asked how they felt about their comfort in understanding the meaning of
hereditary cancer, some provided answers suggesting they understood the meaning while others stated they understood but did not further expand on their understanding. As a result, for some participants their understanding of hereditary cancer may not have been fully assessed. In addition, multiple participants expressed they understood they were at an increased risk for cancer solely based on their family history of cancer and if they were to obtain an uninformative negative genetic test result, their risk would still be based on the family history of cancer.

The last category is general recommendations and is divided into mode of delivery, additional information needed, access barriers, and public use. Participants expressed they would also like the information presented in the tool in different ways such as flyers and pamphlets, a news report, or a testimonial. Some participants expressed they would like to know more information about how GINA (a federal law protecting against genetic test discrimination from employers and health insurance companies) could affect them if revoked or changed. In addition, they were interested in learning how their genetic test information could be utilized by supplemental insurance companies. Furthermore, participants also expressed they would like to know more information about the causes of sporadic cancers such as environmental and lifestyle factors. Participants identified several barriers affecting access to the tool such as not being friendly for the hearing impaired, complexity of information for older individuals who are not familiar with the terminology, and user experience varying by device-use such as font appearing too small on a handphone. Despite these issues, most participants expressed the tool is adequate for general public use.
Table 3. Categorized feedback obtained from semi-structured interviews with representative quotes

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aesthetics</td>
<td>Visual Quality</td>
<td>“I loved the design of the presentation in terms of the visuals from beginning to end. I found it friendly, as if flashy. From the first time I saw it, that was my immediate impression, that it was eye-catching”</td>
</tr>
<tr>
<td></td>
<td>Audio Quality</td>
<td>“Well, the quality could be a little better. The volume sometimes varied depending on some slides where the volume was higher and others were lower and quality was half and half”</td>
</tr>
<tr>
<td></td>
<td>Narrator’s Voice</td>
<td>“It doesn’t bother me, it seems to me that she spoke clearly”</td>
</tr>
<tr>
<td></td>
<td>Complexity or unfamiliarity with language</td>
<td>“If it’s the first time, it might be a little confusing or something, because the language wouldn’t be a normal thing for it, you know”  “Obviously I also think that the person has to have a little, a little bit of knowledge of what genetics is because they’re going to see the term that maybe they’re not going to be very familiar with”</td>
</tr>
<tr>
<td></td>
<td>Easy to understand/simple</td>
<td>“The presentation is extremely well written in terms of carrying in understandable language a lot of information that which is not so simple”  “It seems to me that the information is quite complete and I like that the language is simple, even though the information it is giving is quite detailed information as to what the causes are and how they work.”  “Yes, of course. Its information is clear and simple to understand”</td>
</tr>
<tr>
<td></td>
<td>Value of information</td>
<td>“I think one of the things I remember that I stayed with was that even though I’m a man, I have and have children, including a girl – I think was helpful for me to take the test because it can make an impact. You can give me information for my daughter, even though I am a man.”  “This, which was good for me to be interested in that variant that obviously not right now has been studied, so it is not but, having seen the presentation helped me understand what the [VUS] meant…. I haven’t had the doctor’s appointment yet and have it next week but at least I could get an idea of what it was I was looking at when I saw the results. This I think… I think the presentation is extremely valuable.”</td>
</tr>
<tr>
<td>Comprehension</td>
<td>Understanding of Hereditary Cancer</td>
<td>“Well, as I understood hereditary [cancer] is less possible. Only 10%, right? It is less possible to get it by inheritance.”  “I could put it in simple words, there is genetic information that we can inherit and could or could not develop, but that we are at risk is that we have some predisposition to give that genetic information, yes. As I said, it is a Russian roulette, we can have the gene and not get [cancer]. We can have it, and then get [cancer].”</td>
</tr>
<tr>
<td></td>
<td>Risk Perspective</td>
<td>“Well, because of my family history, I have to be a little more careful than other people have, even though my results of the specific genes that were studied, that are being studied came out negative. This, my family history in that case is the one that predominates so my risk is a little higher than normal”</td>
</tr>
<tr>
<td>General</td>
<td>Mode of Delivery</td>
<td>“I think always that flyers and pamphlets, that kind of thing that is something that really helps with medical issues”  “Look, if there was like an interview, one person [talking] with another, or probably a testimony, like, look, I came out negative and my mom came out positive, it was positive and look, and we took the test, and it turned out that I came out. Huh, uh, uh, do you understand me? So that same one that you explained, but that a person says it, understand, I assure you that I will stay [paying attention] longer”</td>
</tr>
</tbody>
</table>
Table 3. (Continued)

| Additional Information Needed | “If anything, dig a little deeper into the issue of insurance, because i think that’s an area…i don’t know. Maybe if i were the only one who had it but i think that digging a little more to give more security to the people who do contemplate having these exams in the future to give you more assurance that they are protected.” |
| Access Barriers | “If second part says mutations may be caused by errors during cell division or may be caused by exposure to agents in the environment that damage dna… although i don’t know if you’re going to explain what those agents are later, but maybe they’ll explain it later.” |
| Endorsement For General Public Use | “For example, if there is no problem with the mutation part it is a concept that many people understand, but there were other parts such as that or I think if they are…older people who are going to need a little [more] follow-up (in terms of understanding the concepts).” |
| | “If someone sees it as we do not, [they will not] find barriers for someone but for someone who cannot hear it, because it will be difficult to at least hear what the [narrator says] while reading I think not but that is taking into consideration that this community will access this type or this presentation” |
| | “On a phone and the handwriting is smaller than it was when we were in the office” |
| | “I found it very educational, and it seemed like something that should be shared with more people, not only the people who participate in this study, because there are many times that sometimes even in television programs and that makes jokes about it, but that many times people do not understand what it means even the most basic concepts, of negative or positive” |
| | “It’s a good idea that another person before going through this process saw this presentation. It is very informative.” |

Qualitative Themes

Testing benefits family members

When discussing hereditary cancer in general, individuals brought up benefits for family members. One participant stated,

Those who come out with the positive result in the BRCA that we were talking about indicates that when the man, even if [they] don’t have it, that you take it from your mother or from someone, it can affect the little girl of mine that I have , who may have greater possibilities to get [cancer].

This suggest they understood that even if they never developed cancer, their children could be at risk if they were to inherit a mutation in a cancer predisposing gene from him. Another participant stated, “the results help the family.”
Importance of cancer family history

Another emerging theme was the importance of family history in determining cancer risk despite having a negative or VUS test result. Many participants expressed they would still seek cancer screenings and stay on top of their health because they could still be at risk solely based on their family history. For example, a participant stated the following:

This type of sporadic cancer, hereditary, etc. the genetic testing of mutations that when it comes out positive, when the VUS variant comes out, when it is negative, but always taking into consideration the family history of cancer until the end.

Responses to positive genetic test results

There were three types of responses identified with regard to how participants would feel if they received a positive test result. The first is an emotional response like feeling concerned or worried about the results. For example, a participant stated they would feel “Destroyed. I would feel bad. I would feel like worried or very worried” if they obtained a positive result on a genetic test. The second response type suggested some participants were unclear of the meaning of a positive test result. For example, one participant stated they would “fight to have life and see how a proper recovery is possible”. This statement suggests the participant may view their positive genetic test result as if they were given a diagnosis of cancer. Lastly, the third type of response was to describe actions they would take based on learning about a positive test result. This included seeking prevention, speaking with their doctors, and sharing the information with family members. For example, one participant stated:

Well, I think pretty prepared, right? This in the sense of knowing what the next step is and in addition to discussing it with the primary care physician, sharing it with family
members or progeny. My children and the moment I have them let them know this is already genetically proven or you have to be aware.

**Responses to negative genetic test results**

A total of two types of responses were identified regarding negative test results. The first theme was lack of clarity regarding the meaning of the result. One of the participants stated:

Confused with you because if I receive a negative and I am positive for breast cancer. You may be that. Well, I do not know, on the one hand it can be. If I take this out, the negative genetic test and I have cancer, or if it comes out positive for cancer like would my daughters have this. I mean, like how?

This response suggests the participant may not have understood the purpose of genetic testing and the meaning of a genetic test result. The second response is that negative results do not completely eliminate all cancer risks, participants stated they would still seek prevention methods and check-ups. For example, a participant expressed feeling the following in regard to a negative test result:

Fantastic, great, awesome. I would be happy. I would feel more confident but that would not take away my desire to check myself every now and then.

**Responses to VUS genetic test results**

Lastly three responses emerged regarding VUS test results. The first response was trying to make meaning of the result or differentiating it from a positive result. One participant stated

If it’s like what I’ve understood the video, it’s that a random mutation occurred, so it’s not hereditary. It’s not something we inherited from mom or dad, but it was just a mutation that happened randomly in the body and then that genetic change was found in
the test, but you can’t see, you don’t determine that it comes from dad or that it comes from mom.

This response suggests the participant believed a VUS test result as something occurring sporadically that cannot be inherited. Moreover, it seemed they also misunderstood a VUS as a somatic mutation that was picked up on the test. Some understood that with family history of cancer, they could still be at an increased risk of developing cancer and should still seek clinical advice and screenings. For example, one participant stated:

Hoping that maybe the specialist or the doctor will tell me we are going to make you one from here to next year and I am a year again calm waiting to see what happens.

Lastly, many participants expressed they would react to a VUS in a similar way to how they would react with a negative test result while others expressed, they would feel calm and unafraid by the test result. One participant stated “I know I would feel the same way as if I had tested negative” whereas another participant who had already received their test results at the time of the interview stated:

No, it didn’t scare me. I think that if I hadn’t seen the presentation sooner, maybe I would have been scared.
Chapter 4: Discussion

Although the English version of this web-based educational tool has been evaluated amongst English-speaking cohorts as well as Black females (Cragun et. al, 2020; Pal et. al, 2023), this is the first study to pilot the Spanish version of the tool. Our findings show Spanish-speaking participants’ knowledge and feelings of being informed and empowered to decide about genetic testing significantly increased after viewing the tool. In addition, findings from a subset of participants who were subsequently interviewed suggests the tool is appropriate and acceptable for the Hispanic/Latinx population.

The need for Spanish-language hereditary cancer tools is illustrated by the lower rates of genetic testing seen among the Hispanic/Latinx population, that is largely due to a lack of awareness of genetic testing services (Vadaparampil et. al, 2006; Gammon et. al, 2011). However once awareness is raised, Hispanics/Latinx find genetic testing to be useful (Christensen et. al, 2022). Our tool is among only a few Spanish language educational tools on hereditary cancer that have been evaluated in published literature (Hurtado-de-Mendoza et. al, 2020; Nazareth et. al, 2021). One educational intervention which implemented a culturally targeted booklet with information about genetic counseling and testing for Latinas found that for participants who had the intervention, there was greater uptake of genetic counseling and testing compared to the control group which only received a fact sheet containing information about breast cancer survivorship (Conley et. al, 2021). In addition, the study found there was an increase in knowledge related to Hereditary Breast and Ovarian Cancer Syndrome (HBOC) for the intervention group (Conley et. al, 2021). Although our tool shows a significant increase in
knowledge scores from pre to post, it was never intended to alter attitudes or persuade people to pursue genetic testing. Nevertheless, we measured genetic testing attitudes to assess whether they changed, and similar to findings from a study of the English version (Cragun et. al, 2020), our tool did not impact participants’ attitudes about and desire for genetic testing, though many more felt fully informed and empowered to decide about testing after viewing the tool.

Despite significant improvements, only about half of all participants felt fully informed and empowered after viewing the tool. This suggests these individuals may need counseling focused on addressing knowledge and decisional gaps. This contrasts with findings from the study evaluating the English version of the tool where 74% of individuals felt fully informed and empowered to decide about genetic testing after viewing the tool. Some of this difference may be because 29% of the English-speakers were already fully informed and empowered before viewing the tool, as compared to only 15% of Spanish-speakers in this study. The median knowledge scores were also lower in our study before as well as after viewing the tool when compared to the study of the English version of the tool. Although we cannot be sure why the results of the English and Spanish version differ, it may relate to lower health literacy rates, different levels of interest in genetic testing, differences in fear of genetic test results or fear of misuse of genetic information in the Spanish-speaking population (Canedo et. al, 2020; Hamilton et. al, 2016; Kinney et. al, 2010).

Interview responses showcased the tool was valuable and informative for many individuals who clearly seemed to grasp the implications of possible test results. Generally, participants expressed they understood genetic testing could lead to actionable findings with prevention and management guidelines and could also be beneficial for family members. In addition, many participants expressed a negative or VUS test result in light of a family history of
cancer did not negate all cancer risks and they should still follow the appropriate management and seek clinical advice. Nevertheless, a few participants remained confused, suggesting that further clarification of information may be needed after viewing the tool. Misunderstandings included uncertainty about the purpose of genetic testing, as well as confusion between tumor analysis and germline genetic testing. There could have been several reasons why participants became confused such as looking further into the “learn more” feature of the tool. Due to some ongoing confusion, the tool may not be sufficient at providing all individuals with the same level of understanding of genetic testing information and further counseling may be needed to assess for understanding and offer clarification. Several participants in our study seemed to want more clarity related to genetic information privacy laws, and factors influencing the risk of sporadic cancer.

The overall findings suggest this tool has utility and is appropriate for the Hispanic/Latinx population. Nevertheless, recommendations from participants will be used to further improve certain aspects of the tool. These include enhancing audio quality, changing a couple of confusing diagrams, providing additional information needed by participants, clarifying some terminology, and addressing access barriers by adding closed captioning. After improvements are made to the tool based on the feedback received, future studies should be conducted on a diverse Hispanic/Latinx population to ensure adequate representation. The tool can also be studied in a clinical setting to measure changes in uptake of genetic counseling and/or testing.

**Implications for Genetic Counseling Practice**

Given that this tool led to improvements in knowledge of hereditary cancer genetic testing, it could be used by Hispanic/Latinx patients before meeting with a genetic counselor.
Coming in with an understanding may help to reduce the appointment length or allow more time to discuss concerns and questions patients may have. Instead of focusing on providing information to patients during the pre-test counseling session, genetic counselors can focus on addressing their patients’ emotional, social, and/or personal concerns and clarifying any misunderstandings (Samuel et. al, 2017).

Only a small number of genetic counselors provide services in Spanish which does not meet the needs of the Hispanic/Latinx patient population seeking genetic testing (Augusto et. al, 2019). Given inadequate interpreter services and problems with verbal and written communication that Hispanics/Latinx often experience (Hamilton et. al, 2019; Galen et. al, 2015), it is possible that use of this tool could improve quality of the genetic counseling visit. Moreover, the tool may ultimately prove useful for triaging those who may not need pre-test counseling. Specifically, if an individual feels fully informed and empowered to make a decision after viewing the tool and they have sufficient understanding, they may not need further counseling which would reduce the number of patients who would need to meet with a genetic counselor.

**Strengths and Limitations**

Both the quantitative and qualitative data provided unique insights related to the impact and appropriateness of the tool for the Spanish-speaking population. In addition, the feedback obtained will be used to further improve the tool. Based on known published literature, this is the first study to evaluate a tool containing the educational information that is part of the cancer pre-test genetic counseling session (Beauchesne et. al, 2023). Despite these strengths this study should be evaluated in light of certain limitations. First, generalizability is limited given the pilot population was relatively small and most were Caribbean Islanders with high educational levels.
In addition, the knowledge questionnaire used was not previously validated in Spanish and consisted of 10 questions. However, in our study only 9 questions out of the 10 were used because of an error that was not identified when transferring the question online.
Chapter 5: Conclusion

Study findings show that a Spanish-language web-based tool for hereditary cancer significantly increases participants knowledge and feelings of being informed and empowered to decide about genetic testing. Furthermore, the tool was well received overall and deemed appropriate and usable for the Hispanic/Latinx population although there are aspects that will be improved. Ultimately, this tool shows potential for supplementing the informational portion of a pre-test genetic counseling session for the Hispanic/Latinx population.
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Appendix A:

English Interview Guide

Material utilized and adapted from Alastre (2021).

Introductory Script:

[Greeting] Mrs./Ms./Mr. [First Name Last Name],
My name is Gretter Manso and I’ll be your interviewer today for the Piloting Study of a Spanish-Language Educational Tool for Hereditary Cancer study.
Thank you for completing the survey portion of this study, and for taking the time to speak with me today. Today you will be watching the educational tool you previously saw, along with some options to view additional educational information. I will ask you questions before, during, and/or after you view it. I am interested in finding out about your opinions of the tool; therefore, there are no wrong answers to these questions. As you may recall from the consent form that you read before you completed the first part of the study, we plan to record and transcribe this interview. We will not include your name or any identifying information with this interview. You may ask me to skip a question if you are uncomfortable, or you are free to ask me to stop recording at any time during the interview. Do you still want to proceed with this interview?

Do you have any questions before we begin the interview?
[Address any questions or concerns]

I will now start the recording then we will begin.

Content Questions:

1. Can you describe for me your overall impression of the educational tool?
   a. Probe: What did you think about the tool?
   b.Probe: Did you find the tool informative?

2. Can you describe for me what information in the educational tool you found most useful?
   a. Probe: What information did you learn from the tool?
   b. Probe: What did you learn about genetic testing?

3. Can you describe for me what information in the educational tool you found least useful?
   a. Probe: What information bored you?
   b. Probe: Was there any information repetitive to what you’ve heard outside of viewing this tool?

4. Can you describe for me any parts of the educational tool that were hard to understand or unclear?
   a. Probe: Was any information overwhelming?
b. Probe: Was there language used that you did not understand?
c. Probe: Were there specific slides that you did not understand?
d. Probe: Were there parts of the tool that did not make any sense to you?

5. Can you explain for me what additional information you wished the educational tool would have covered?
a. Probe: What questions about genetic testing do you still have?
b. Probe: What did the tool not cover that you wish it had?

6. Can you explain for me what information you wished the educational tool did not cover?
a. Probe: What information did you find to be irrelevant?
b. Probe: What information was unnecessary to know about?

Visual/Graphical Questions:
1. Can you describe for me what you thought about the appearance and design of the educational tool?
a. Probe: Was the tool easy to view?
b. Probe: Did you like the graphics?
c. Probe: Could you read everything on the slides?

2. As you watched the educational tool, did you skip over any slides?
a. [If yes]:
i. Why did you skip over [list the slides]?

3. Did you repeat any slides?
a. [If yes]:
i. Why did you repeat [list the slides]?

4. Can you describe for me what you thought about the flow of the educational tool?
a. Probe: Did the information progress well?
b. Probe: Was the order of the information good?
c. Probe: Did the tool begin well?
d. Probe: Did the tool end well?

5. Can you describe for me what you thought about the voiceover for the educational tool?
a. Probe: Did you understand what was spoken to you?
b. Probe: Did you like the tone of the speaker?

Educational Questions:
1. Can you describe for me how confident you feel about now knowing what hereditary cancer is?
a. Probe: Do you feel you could explain hereditary cancer to someone else confidently, like a relative?
b. Probe: How did this educational tool changed your perception of inherited cancer?
2. Can you describe for me what you think about your risk of hereditary cancer is compared to the general population?
   a. Probe: Do you think you are at higher or lower risk for hereditary cancer compared to others?

3. Can you describe for me how well you feel this educational tool prepared you to learn about a potential positive genetic test result?
   a. Probe: How would you feel if you received a positive result?
   b. Probe: Did the tool help you feel better prepared to learn about a VUS result?

4. Can you describe for me how well you feel this educational tool prepared you to learn about a potential variant of uncertain significance genetic test result?
   a. Probe: How would you feel if you received a VUS result?
   b. Probe: Did the tool help you feel better prepared to learn about a VUS result?

5. Can you describe for me how well you feel this educational tool prepared you to learn about a potential negative genetic test result?
   a. Probe: How would you feel if you received a negative result?
   b. Probe: Did the tool help you feel better prepared to learn about a negative result?

**Slide-Specific Questions:**
1. Based on the first few slides explaining what inherited cancer is (slides 2-5), can you describe for me how else you would want information about inherited cancer explained to you?
   a. Probe: What additional information do you wish was covered when initially explaining what inherited cancer is?

2. When thinking about the slides on types of inherited cancer genes and their affect (slides 6-9), can you describe for me how else you would want information about hereditary cancer genes explained to you?
   a. Probe: What else do you need to know about the types of hereditary cancer genes people can have?

3. When thinking about the slides on types of genetic testing (slides 10-13), can you describe for me how else you would want information about genetic testing options explained to you?
   a. Probe: What else do you need to know about genetic testing in order to feel confident in or comfortable with having this type of testing?

4. When thinking about the closing slides (slides 14-17), can you describe for me how else you would want information about GINA, genetic testing cost, and genetic testing expectations explained to you?
   a. Probe: What else do you wish was explained to you about genetic testing laws, cost, or expectations?

5. What did you think of the “learn more” slides?
   a. Probe: Did you go look at these slides?
Looking Forward Questions:
1. After seeing this video, did you feel interested in scheduling an appointment with a genetic counselor?
2. Can you describe for me any barriers you think there would be to using this educational tool for others who wanted to have genetic testing?
   a. Probe: Do you think this tool could be used for the general public wanting to get genetic testing?
   b. Probe: What issues do you think there would be with using this tool for everyone wanting to get genetic testing?
3. Can you describe for me any other ways you would want information about inherited cancer explained to you?
   a. Probe: Are there better ways to provide information about inherited cancer to people, rather than a tool like this?
   b. Probe: Would you rather have information given to you in person or through printed materials?
4. Can you describe for me any other ways you think this educational tool could be improved?
   a. Probe: How else could it be organized?
   b. Probe: How else would you like the navigation to be?

Closing Script:
Thank you for your time to speak with me today and for watching the educational tool! All the information you have provided is extremely helpful to our research efforts and to helping improve this education tool. Please feel free to contact me or the study team by phone or email if you have any questions in the future. I wish you a great rest of your day!

NOTES ABOUT INTERVIEW (interviewer’s reflection/observation):
Appendix B:

Pre-tool Survey

Material utilized and adapted from Alastre (2021)

Please answer the following questions to the best of your ability.

What language do you prefer to receive health information? (i.e. pamphlet and/or brochures) (Please check one)
☐ Spanish
☐ English

☐ Other: ______________

☐ Both English and Spanish

Do you live in the U.S. including Puerto Rico?
☐ Yes
☐ No

Which of these categories best describes your medical status? (Please check one)
☐ I have never been diagnosed with cancer before
☐ I do not currently have cancer but I have been diagnosed with cancer before
☐ I am currently being treated for cancer

Have you had a family member diagnosed with cancer? (Please check one)
☐ Yes
☐ No
☐ I don’t know

If you marked yes to the question above, please indicate who in your family has had cancer, and write the type of cancer in the line provided (check all that apply)
☐ Mother ______________
☐ Father ______________
☐ Brother ______________
☐ Sister ______________
☐ Paternal Grandmother ______________
☐ Paternal Grandfather ______________
☐ Maternal Grandmother ______________
☐ Maternal Grandfather ______________

☐ Other: ______________
☐ If you have more than one brother or sister who has or has had cancer, please list them all here:

________________________________________________________________________________________

What type of cancer(s) have you had or are you being treated for? (Check all that apply. If you have not had cancer, please select none)
☐ none ☐ breast cancer ☐ ovarian cancer ☐ colorectal cancer ☐ prostate cancer
☐ pancreatic cancer ☐ Unsure ☐ other cancer (please list)__________

Have you had inherited cancer genetic testing done before? (Please check one)
☐ Yes
☐ No
☐ I don’t know

Has anyone in your family had inherited cancer genetic testing done before? (Please check one)
☐ Yes
☐ No
☐ I don’t know

How old are you currently? (Please check one)
☐ 18-29 ☐ 30-39 ☐ 40-49 ☐ 50-59
☐ 60-69 ☐ 70-79 ☐ 80-89 ☐ Age 90 or older

Which of these categories describe you? (Check all that apply)
☐ South American ☐ North American (Mexican) ☐ Spanish (From Spain)
☐ Central American ☐ Caribbean Islander ☐ I prefer not to answer
☐ North American (Born in the U.S. or Canada)
☐ Some other race, ethnicity or origin (please list here) ____________

What is the last grade or level of school you have completed? (Please check one)
☐ Attended but did not complete high school ☐ Did not attend high school ☐ High school or GED
☐ Some college
☐ Graduated college ☐ Completed postgraduate degree ☐ Other (please list) ____________

What is your gender? (Please check one)
☐ Male ☐ Female ☐ I prefer not to answer ☐ Other (please list) ____________
The following questions are about genetic testing that can be done to find out if a person has a nonworking gene that is associated with a higher risk to develop breast and colon cancer. Please answer “Agree” if you agree with the statement or “Disagree” if you disagree. If you are not sure please choose “Don’t know”.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most cancer is caused by a nonworking cancer gene that can be passed on to children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If a person has a nonworking cancer gene that puts them at a higher risk to develop breast or colon cancer, there is usually nothing they can do about it.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finding a difference in a cancer gene that we don’t yet know how to interpret (whether good or bad) will usually explain why someone got cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic test results in the United States can be used to decide if someone can get health insurance in most cases</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Testing can find nonworking genes that are unexpected or that do not explain the cancers in a person's family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In most cases it is against United States’ law to use a genetic test result to deny life and disability insurance coverage or raise the cost of these policies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The sister or brother of a person with an inherited nonworking cancer gene usually has a 50% chance of having the same mutation</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Some people with an inherited nonworking cancer gene will never get cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic testing for inherited cancer risk genes is not usually helpful when a person already has cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please answer the following question
<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time (☐)</th>
<th>A little of the time (☐)</th>
<th>Some of the time (☐)</th>
<th>Most of the time (☐)</th>
<th>All of the time (☐)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you have problems learning about a medical condition because of difficulty understanding written information.</td>
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<td></td>
</tr>
</tbody>
</table>

Please answer the following questions about genetic testing for hereditary cancer.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes (☐)</th>
<th>No (☐)</th>
<th>Unsure (☐)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know the benefits and risks of the genetic testing options.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am clear about which benefits and risks matter most to me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have enough support and advice to make a choice.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel sure about the best choice for me.</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

For each statement below, please check the box that best shows how you feel about genetic testing for hereditary cancer.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree (☐)</th>
<th>Agree (☐)</th>
<th>Unsure (☐)</th>
<th>Disagree (☐)</th>
<th>Strongly Disagree (☐)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe genetic testing will be useful for me</td>
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<td></td>
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<tr>
<td>Having genetic testing is important to me</td>
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<td></td>
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<tr>
<td>I want to have genetic testing</td>
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</tbody>
</table>

Genetic counseling is the process of advising individuals and families affected by or at risk of genetic disorders to help them understand and adapt to the medical, psychological and familial implications of genetic contributions to disease.

For each statement below, please check the box that best shows how you feel about your intention to see a genetic counselor and/or have genetic testing in the next three months.
<table>
<thead>
<tr>
<th></th>
<th>Not at all likely</th>
<th>Not very likely</th>
<th>Somewhat likely</th>
<th>Very likely</th>
<th>Extremely likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the next three months, how likely are you to have genetic counseling?</td>
<td></td>
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</tr>
<tr>
<td>In the next three months, how likely are you have genetic testing?</td>
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</table>
Appendix C:

Post-tool Survey

Material utilized and adapted from Alastre (2021).

The following questions are about genetic testing that can be done to find out if a person has a nonworking gene that is associated with a higher risk to develop breast and colon cancer. Please answer “Agree” if you agree with the statement or “Disagree” if you disagree. If you are not sure please choose “Don’t know”.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
<th>Don’t Know</th>
</tr>
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<tr>
<td>Most cancer is caused by a nonworking cancer gene that can be passed on to children</td>
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<tr>
<td>If a person has a nonworking cancer gene that puts them at a higher risk to develop breast or colon cancer, there is usually nothing they can do about it.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Finding a difference in a cancer gene that we don’t yet know how to interpret (whether good or bad) will usually explain why someone got cancer</td>
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<tr>
<td>Testing can find nonworking genes that are unexpected or that do not explain the cancers in a person's family</td>
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<td></td>
<td></td>
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<tr>
<td>In most cases it is against United States’ law to use a genetic test result to deny life and disability insurance coverage or raise the cost of these policies</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>The sister or brother of a person with an inherited nonworking cancer gene usually has a 50% chance of having the same mutation</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please answer the following questions about genetic testing for hereditary cancer.

I know the benefits and risks of the genetic testing options.  
- Yes ☐
- No ☐
- Unsure ☐

I am clear about which benefits and risks matter most to me.  
- Yes ☐
- No ☐
- Unsure ☐

I have enough support and advice to make a choice.  
- Yes ☐
- No ☐
- Unsure ☐

I feel sure about the best choice for me.  
- Yes ☐
- No ☐
- Unsure ☐

For each statement below, please check the box that best shows how you feel about genetic testing for hereditary cancer.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe genetic testing will be useful for me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Having genetic testing is important to me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I want to have genetic testing</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Genetic counseling is the process of advising individuals and families affected by or at risk of genetic disorders to help them understand and adapt to the medical, psychological and familial implications of genetic contributions to disease.

For each statement below, please check the box that best shows how you feel about your intention to see a genetic counselor and/or have genetic testing in the next three months.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all likely</th>
<th>Not very likely</th>
<th>Somewhat likely</th>
<th>Very likely</th>
<th>Extremely likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the next three months, how likely are you to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

38
have genetic counseling? |  |  |  |  
In the next three months, how likely are you have genetic testing? |  |  |  |  

**AIM/IAM QUESTIONS**

*Please rate each statement based on whether you completely disagree, disagree, neither disagree nor agree, agree, or completely agree. We would like to know what you think overall about this video.*

<table>
<thead>
<tr>
<th>AIM/IAM</th>
<th>Completely Disagree</th>
<th>Disagree</th>
<th>Neither Disagree nor Agree</th>
<th>Agree</th>
<th>Completely Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIM</td>
<td>This video meets my approval</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>This video is appealing to me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>I like this video</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>I welcome this video</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>IAM</td>
<td>This video seems fitting</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>This video seems suitable</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>This video seems applicable</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>This video seems like a good match</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

On a scale of 1 to 10 (*10 being the highest*) how would you rate your satisfaction with this video?

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5  ☐ 6  ☐ 7  ☐ 8  ☐ 9  ☐ 10

Please tell us how we can improve the educational video you watched:

_________________________________________________________

Please tell us what you disliked and liked about the educational video you watched:
If you would like to participate in a short interview to provide feedback about this educational tool, please write your email in the line below. All participants selected for an interview will receive a $20 Amazon or Walmart gift card.
Appendix D:

Material Use Permission Email

Thursday, March 16, 2023 at 10:10:32 Eastern Daylight Time

Subject: RE: EXT: Thesis Material
Date: Thursday, March 16, 2023 at 10:03:47 AM Eastern Daylight Time
From: Alastre Arcusa, Stefania
To: Gretter Manso

Hi Gretter,

You have my permission for this. Thank you,

Stefania Alastre
Genetic Counselor
813-745-7241

From: Gretter Manso <gretter@usf.edu>
Sent: Thursday, March 16, 2023 9:56 AM
To: Alastre Arcusa, Stefania <Stefania.AlastreArcusa@moffitt.org>
Subject: EXT: Thesis Material

Hi Stef,

I would like to ask for permission to utilize some of the material you used for your thesis at USF “Evaluation of a Spanish-language Educational Tool.” This material would only include the interview guide, pre-tool questionnaire, and post-tool questionnaire.

Thank you!

Regards,

Gretter Manso
Genetic Counseling Graduate Student
University of South Florida
gretter@usf.edu

This transmission may be confidential or protected from disclosure and is only for review and use by the intended recipient. Access by anyone else is unauthorized. Any unauthorized reader is hereby notified that any review, use, dissemination, disclosure or copying of this information, or any act or omission taken in reliance on it, is prohibited and may be unlawful. If you received this transmission in error, please notify the sender immediately. Thank you.
Appendix E:

IRB Approval Letter

This study was approved by USF IRB as a continuation of the thesis project by Alastre (2021). Below is her IRB approval letter.

Dear Stefania Alastre:

On 8/20/2020, the IRB reviewed and approved the following protocol:

<table>
<thead>
<tr>
<th>Application Type:</th>
<th>Initial Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRB ID:</td>
<td>STUDY001215</td>
</tr>
<tr>
<td>Review Type:</td>
<td>Exempt(2)(3)</td>
</tr>
<tr>
<td>Title:</td>
<td>Evaluation of a Spanish-language Educational Tool for Inherited Cancer</td>
</tr>
<tr>
<td>Funding:</td>
<td>Florida Association of Genetic Counselors</td>
</tr>
</tbody>
</table>

The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

Sincerely,
Katrina Johnson
IRB Research Compliance Administrator