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Exploration of Patient Communication Preference Regarding Reclassified Genetic Test Results

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EXPLORATION OF PATIENT COMMUNICATION PREFERENCE REGARDING RECLASSIFIED GENETIC TEST RESULTS

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ABSTRACT

Genetic testing is becoming increasingly used to detect individuals who are predisposed to developing cancer. If genetic testing identifies a variant in an individual's DNA, the testing laboratory uses available data to classify the variant as either disease-causing or benign. When limited data is available regarding a variant's pathogenicity and the risk of cancer for an individual is not clear, the variant is classified as a "variant of uncertain significance" (VUS). If new data is discovered, the VUS may be reclassified. There is a gap in current literature regarding desired communication for a reclassified genetic test result. There are no standard guidelines for healthcare providers regarding communication of a reclassified VUS result. This study aimed to explore communication preferences of past Prisma Health patients with a VUS result on cancer genetic testing. A total of 34 participants responded to the anonymous online questionnaire. Participants reported telephone call by a genetic counselor as the most preferred communication for an upgraded VUS result and a letter in the mail as the most preferred communication for a downgraded VUS result. There was no significant difference in communication preferences for upgraded versus downgraded VUS results. A majority of participants reported mild concern regarding their VUS result. Overall, this study determined that patients want to be contacted regarding a reclassified VUS result, but there is no clear consensus on the most preferred method.

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CHAPTER 1

BACKGROUND

The molecular basis of cancer is fundamentally 'genetic' at the cellular level- all tumors are caused by mutations in either proto-oncogenes or tumor suppressor genes (Evans & Woodward, 2020). Most of these mutations are acquired throughout one's lifetime and cannot be passed on to future generations. However, mutations in a proto-oncogene or tumor suppressor gene can sometimes be inherited. Of all cancer diagnoses, about 5-10% have a genetic predisposition. Having mutations present in certain genes increases one's risk of developing certain types of cancer (Domchek et al., 2013). Identifying patients with genetic predispositions to cancer is clinically important to help guide treatment, make surgical decisions, and test at-risk family members (Evans & Woodward, 2020). Cancer research continues to identify more genes that are associated with an increased risk for developing cancer in the presence of a mutation.

Germline genetic testing is used in the oncology setting to help identify individuals who are predisposed to developing cancer. Germline genetic testing requires DNA samples that can typically be obtained from blood, saliva, or fibroblasts. A genetic test can be ordered to analyze one specific gene mutation through single site testing, or it can be ordered as a multi-gene panel to analyze many genes at one time. Different laboratories have different genes on their panels and each gene is associated with a specific cancer risk profile (Hiraki et al., 2014). The genetic test is typically done by next generation sequencing (NGS), which identifies specific inherited variants in a person's

genes. NGS is a massive parallel sequencing technology that allows large amounts of genetic information fragments (DNA and RNA) to be sequenced simultaneously (Shendure & Ji, 2008). The field of medical genetics continues to evolve and advance, which allows for lower costs of genetic testing and more rapid results from NGS (Rehm et al., 2013). These factors are thus leading to more individuals choosing to undergo genetic testing in many specialties, including cancer. The use of genetic testing in medicine is beneficial to a patient because it can help inform healthcare management (Esterling et al., 2020).

1.1 Variant Interpretation

When genetic testing is completed, the final report describes the interpretation of variants detected. Variant interpretation is used to classify a variant based on where it falls on a scale from disease-causing to benign. The classification of a variant is based on different criteria. Some factors that are assessed include population data, computational data, functional data, and segregation data. There are many classification systems offered for annotating genetic variants (Halverson, 2019; Shoenbill et al., 2014). A five-tier terminology system is strongly recommended by the American College of Medical Genetics and Genomics (ACMG) (Richards et al., 2015). The five-tier classification system gives a variant one of five modifiers: pathogenic, likely pathogenic, uncertain significance, likely benign, or benign. ACMG recommends using the word “likely” as a variant’s modifier only when the interpretation is at least 90% certain that the variant is disease-causing or harmless (Richards et al., 2015). The five-tier classification system is used to assist healthcare providers in understanding pathogenicity of a variant and to make management recommendations based on the findings.

When a variant is “pathogenic” or “likely pathogenic,” there is sufficient evidence to assume a clinical effect from the variant. For genes that regulate cell growth, a pathogenic variant puts an individual at a higher risk of developing cancer. The healthcare team may use a “pathogenic” or “likely pathogenic” variant to make surgical decisions, implement risk-reducing strategies, and increase screenings. When a “pathogenic” or “likely pathogenic” variant is identified, testing should be offered to family members who may also be at increased risk (Chang et al., 2019). A pathogenic variant is reported to represent less than 20% of variants in high-risk cancer genes (Moghadasi et al., 2016).

Two other possible variant classifications include “likely benign” and “benign.” These variants are often not reported to patients and their genetic test result is described to be negative, with no variants identified that would indicate the patient has a higher risk to develop cancer (Susswein et al., 2016). The healthcare team usually recommends against making surgical decisions based solely on a negative genetic test report. A patient’s personal and family history is typically utilized to guide their management.

1.2 Variant of Uncertain Significance (VUS)

The fifth classification on the five-tier system is a variant of “uncertain significance” (VUS). This classification is used when there is limited data available on the pathogenicity of the variant and the impact on the individual’s cancer risk is unknown (Lazaridis et al., 2016; Richards et al., 2015). Often, uncertain variants are lacking data on the impact the variant has on the resulting protein and/or its function, and therefore the clinical effect is unable to be determined. VUS results consist mainly of missense mutations, meaning a single nucleotide is different from the reference sequence, which

may lead to an incorrect amino acid. Occasionally, variants can be found to disrupt RNA splicing, but the end effect is unknown (Eggington et al., 2013). It is not recommended that medical management recommendations for patients be made based on a VUS result alone since there is a lack of information surrounding the variant (Makhnoon et al., 2019). Similar to a negative result, the person should be managed based on their personal and family history. When a person is found to have a variant that is classified as a VUS, it is not typically recommended that other family members undergo genetic testing for the specific variant (Gradishar et al., 2020). Patients who have a VUS result have reported feeling distrust towards healthcare providers, uncertainty surrounding the results and the impact on their clinical management, and concern for their family's risk (Makhnoon et al., 2019). VUS results are monitored by the testing laboratory and will be reclassified if new data is introduced that allows the uncertain result to become a definitive answer. Family studies or other research options may be available to some patients who have a VUS result to aid variant reclassification efforts (Garrett et al., 2016).

1.3 VUS Rates

With the increasing rate of referrals to genetics and better access to genetic counseling services, more people are able to pursue genetic testing. This increase leads to a higher diagnostic yield, along with an increase in discovery of new unclassified genetic variants, which are often labeled as variant(s) of uncertain significance (VUS). Additionally, with the integration of multi-gene panel testing, there have been more VUS reports because of an increase in unique variants being discovered (Medendorp et al., 2018). One study by Federici and Soddu (2020) analyzed panel testing results for hereditary breast and ovarian cancers and concluded that NGS is able to find many

variants, but 40% of those are classified as variants of uncertain significance. However, as more data is gathered for different genes and technology improves, the chance of identifying a VUS decreases because the interpretation of variants improves (Karam et al., 2019; Mauer et al., 2013). Myriad Genetics reports lower VUS results for the *BRCA1* and *BRCA2* genes because of decades of genetic testing they have done, allowing for more research and data of the two genes (Cheon et al., 2014). Eggington et al. (2013) reported that Myriad Genetics' VUS rates went from 12.8% to 2.1% for *BRCA1* and *BRCA2* from 2002 to 2013. Although there are guidelines for variant classification, clinical molecular genetic laboratories can classify variants differently depending on their internal data (Hoskinson et al., 2018).

With advancement of RNA genetic testing, Ambry Genetics has begun to use DNA and RNA analysis to improve diagnostic outcome of DNA genetic testing (Karam et al., 2019). RNA analysis can provide information about the functional status of a DNA variation. It has been estimated that 15% to 25% of DNA variants found in hereditary cancer genes are known to interrupt RNA splicing, but the alterations were classified as a VUS because of missing functional status of RNA (Karam et al., 2019). RNA genetic testing was able to clarify 88% of inconclusive genetic testing results found from DNA in a small sample (Karam et al., 2019). As new information becomes available, a VUS may be reclassified to any one of the other classifications. Reclassification of a VUS result could have implications for a patient and other family members (Murray et al., 2011).

1.4 Variant Reclassification

Variant reclassification does not frequently occur; however, clinical management recommendations for patients and relatives may change if a variant's classification is

reclassified (Mersch et al., 2018; Slavin et al., 2019). A reclassification of a VUS may occur, although for more rare variants, reclassification may never happen (Lindor et al., 2013). In 2018, a retrospective analysis was done to determine the prevalence of variant reclassifications following cancer genetic testing. Of the 1.67 million tests analyzed, only 24.9% of results were reclassified (Mersch et al., 2018). A majority of variants of uncertain significance were downgraded to "likely benign" or "benign". A variant is downgraded when sufficient data is available to support decreasing the level of pathogenicity originally assigned. A variant can be upgraded, but studies indicate this happens less often (Mersch et al., 2018). A VUS can be upgraded when enough data becomes available to support that a variant is deleterious, an alteration that increases one's susceptibility to developing cancer. A VUS that becomes likely pathogenic or pathogenic may have clinical management recommendations not previously indicated for the patient. The patient may be eligible for additional interventions to lower their risk of developing cancer, preventing it from occurring, or detecting it at an earlier stage. Additionally, family cascade testing can be considered (Halverson, 2019; Halverson et al., 2020). For a reclassified genetic test result, ACMG released a statement declaring clinical laboratories have a responsibility to issue formal variant results (including reclassified and updated variant interpretations) to clinicians. ACMG also suggested that laboratories update the information on public databases with a summary of the evidence that led to the classification or reclassification (Deignan et al., 2019).

1.5 Genetic Testing Pretest and Posttest Counseling

Clinically, there are complexities and limitations surrounding genetic testing for cancer predispositions, so it is important to have clear pretest and posttest counseling.

The standard of care in clinical practice is that a certified genetic counselor or other clinical genetics specialist should disclose genetic test results (Roberts et al., 2010). During pretest counseling, it is crucial to inform the patient of possible results, including a VUS result. Additionally, posttest counseling is important to educate patients about their result, including implications and limitations of the test. For posttest counseling, it is the healthcare provider's responsibility to attempt to contact the patient to inform them of their genetic testing results (Patrick-Miller et al., 2014). In the case of a reclassification, the healthcare provider has an ethical obligation, based on the principle of beneficence, to at least try to re-contact a patient in situations that may alter medical care (David et al., 2018).

1.6 Patient Communication

Delivery of healthcare information is important to establish patient-provider confidence. To have an effective healthcare appointment, there needs to be positive patient-physician interaction that is built on trust, communication, and fair intervention (LaRocque et al., 2015). It is critical that providers share results of a test in the most confidential and patient-oriented method (Boohaker et al., 1996). Liederman and Morefield (2003) investigated the preferred communication method of patients who visited their primary care physician's office. This revealed that patients are comfortable getting results through password-protected patient portals, which is sometimes preferred over a phone call (Liederman & Morefield, 2003). Alternatively, studies have compared delivering information over the phone versus in person, which determined that sharing results from a cancer susceptibility genetic test has the same impact when delivered in person or over the phone (Jenkins et al., 2007; Platten et al., 2012). Another study was

done to investigate patient satisfaction with in-person versus telephone delivery of results. The survey was mailed to 379 patients, some of whom had in person result disclosure while others had telephone result disclosure. All patients had *BRCA1* and *BRCA2* genetic testing done at a cancer clinic. In general, they concluded that patients reported being satisfied with their result disclosure and there was no significant difference in satisfaction between patients who received the result in person compared to over the telephone (Baumanis et al., 2009). Additionally, LaRocque et al. (2015) researched patient's preferences for receiving reports of test results. This was done by surveying 409 participants who reported their comfort level of many communication preferences for a variety of test results including blood cholesterol, colonoscopy, sexually transmitted infections, and genetic test results. This study suggested the comfort level of method of communication was affected by the type of test result being disclosed. It was found that 32.6% of patients surveyed were comfortable with a voicemail for common test results, but only 18.1% were comfortable with a voicemail for genetic test results. Higher levels of comfort were noted for the use of password protected portals- 58.8% of patients surveyed were comfortable with portals for common test results and 46.3% were comfortable for genetic test results. The study also found that as a patient's age increases, the comfort level with receiving a letter increases (LaRocque et al., 2015).

In 2019, a study was conducted to see how different communication techniques of cancer screening results affected patient's anxiety, understanding, and preferences. This showed that communication through direct methods (i.e., telephone or in person) were preferred and led to better understanding of the results compared to the less direct methods of communication (i.e., letter in the mail). The study could not make a clear

conclusion of which communication technique would result in less anxiety (Williamson et al., 2019). When returning test results, they need to be communicated clearly and accurately to help reduce a patient's anxiety while also increasing their understanding of the result (Litchfield et al., 2014). Marcus et al. (2012) performed a study to determine women's preferences of learning their mammogram results. This study found that direct verbal communication of results with printed supporting material was preferred because of the complexities that were discussed. The study found that there was a misunderstanding of only a result letter due to patient misinterpretation of the language utilized by the healthcare provider (Marcus et al., 2012). Studies have shown that misinterpretation of patient letters can be caused by the content included and language used; researchers concluded that this is due to the education level of the patient (Marcus et al., 2012; McCaffery & Irwing, 2005). The misinterpretation of letters was seen less frequently when a patient received a call first followed by a letter (Williamson et al., 2019).

Though there is some research regarding a patient's preference for receiving test results, there is a gap in the literature regarding desired communication for a reclassified genetic test result. There is no research, to our knowledge, that has been conducted to assess patient communication preferences for a reclassified VUS genetic test result. There are currently no standard guidelines for healthcare providers regarding method of delivery of reclassified results (Halverson et al., 2019). VUS results are reclassified more frequently because of the increased information being learned and advances in technology (Karam et al., 2019). Although there are more VUS results being reclassified, there is no standard method for communication of this updated information to patients.

When trying to establish a communication method for patients, it is important to consider how a patient prefers to be told of their reclassified result. Overall, it would benefit patients for cancer genetic counselors to have a standardized method of disclosing reclassified VUS test results to ensure consistent and effective communication for all patients.

1.8 Aim of Study

This study utilized an original questionnaire with questions designed to assess primarily quantitative data. The goal of the questionnaire was to ask Prisma Health Genetic Counseling patients with a VUS result on cancer genetic testing to reflect upon preferred communication strategies if their results were to be reclassified. Patients may ultimately benefit by their communication preferences being taken into consideration in clinical practice. Additionally, cancer genetic counselors may benefit from this study as the findings are expected to directly impact their clinical practice.

CHAPTER 2

EXPLORATION OF PATIENT COMMUNICATION PREFERENCE REGARDING RECLASSIFIED GENETIC TEST RESULTS[1]

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2.1 Abstract

Genetic testing is increasingly used to detect individuals who are predisposed to developing cancer. If genetic testing identifies a variant in an individual's DNA, the testing laboratory uses available data to classify the variant as either disease-causing or benign. When limited data is available regarding a variant's pathogenicity and the risk of cancer for an individual is not clear, the variant is classified as a "variant of uncertain significance" (VUS). If new data is discovered, the VUS may be reclassified. There is a gap in current literature regarding desired communication for a reclassified genetic test result. There are no standard guidelines for healthcare providers regarding communication of a reclassified VUS results. This study aimed to explore communication preferences of past Prisma Health patients with a VUS result on cancer genetic testing. A total of 34 participants responded to an anonymous online questionnaire. Participants reported telephone call by a genetic counselor as the most preferred communication for an upgraded VUS result and a letter in the mail as the most preferred communication for a downgraded VUS result. There was no significant difference in communication preferences for upgraded versus downgraded VUS results. A majority of participants reported mild concern regarding their VUS result. Overall, this study determined that patients want to be contacted regarding a reclassified VUS result, but there was no clear consensus on the most preferred method.

2.2 Introduction

Having a mutation or a harmful variant present in certain genes is known to increase one's likelihood of developing certain types of cancer (Domchek et al., 2013). Of all cancer diagnoses, about 5-10% are found to have a genetic predisposition.

Germline genetic testing is offered to people with specific personal or family histories of cancer. The testing is typically done by Next Generation Sequencing (NGS) and is used to assess for inherited pathogenic variants to help identify individuals who are predisposed to developing cancer. This information can be helpful for patient's medical management and for informing family members who may also have a genetic predisposition. After genetic testing is completed, the final report includes a detailed interpretation of detected variants.

Variant classification is based on criteria that determines where the variant falls on a scale from deleterious to benign. The American College of Medical Genetics and Genomics (ACMG) recommends laboratories use the five-tier terminology system for classifying variants (Richards et al., 2015). Through the use of the five-tier classification system, a variant is labeled with one of five modifiers: pathogenic, likely pathogenic, uncertain significance, likely benign, or benign. A variant that has been classified as "pathogenic" or "likely pathogenic" had sufficient evidence known to the laboratory allowing for it to be designated as clinically significant. Variants that are categorized as "likely benign" and "benign" are often reported to patients as a negative test result. This means that no variant was identified to indicate the patient had a higher risk of developing cancer (Susswein et al., 2016). For patients with a variant that was found to be "likely benign" or "benign", it is typically recommended they base their medical management on the patient's personal and family history. The fifth category on the five-tier system is "uncertain significance" (VUS). When a laboratory has limited data available for the variant's pathogenicity and the impact towards the individual's risk for cancer is unknown, then the variant is classified as a VUS (Lazaridis et al., 2016;

Richards et al., 2015). Currently, it is not recommended that a patient's medical management be changed and/or made based on a VUS result alone (Makhnoon et al., 2019).

More people have the opportunity to pursue genetic counseling due to increased rate of referrals and more ways to access this service. This leads to more people undergoing genetic testing, which results in increased diagnostic yield. Additionally, there is an increase in the detection of novel unclassified genetic variants, which often have limited functional information, resulting in a VUS classification. VUS results are continuously monitored by the testing laboratory. If new data is discovered that allows the uncertain result to become more definitive, then the VUS will be reclassified to one of the other classifications (Garrett et al., 2016). VUS reclassification may impact medical management for the patient and other family members (Murray et al., 2011). A majority of VUS results that are reclassified become downgraded to "likely benign" or "benign", which means sufficient data became available to suggest little or no clinical effect from the variant. Other VUS results may be upgraded, but studies indicate this happens less often (Mersch et al., 2018). A VUS is upgraded when data proves that the variant is harmful. When a VUS is upgraded, there may be changes made to their medical management and appropriate family testing may be considered (Halverson, 2019; Halverson et al., 2020).

When giving healthcare information to patients, it is imperative to have established patient-provider confidence. This means that the healthcare provider was able to build trust with the patient, have clear communication, and fair intervention (LaRocque et al., 2015). When sharing test results, it is important that providers share the results

confidentially and in a patient-oriented manner (Boohaker et al., 1996). One way to ensure that healthcare providers share test results with a patient-oriented method is by considering preferred communication techniques. Studies have compared patient preference for receiving information over the phone versus in person. These studies revealed that disclosing cancer susceptibility genetic test results in person or over the phone had the same impact on patients (Jenkins et al., 2007; Platten et al., 2012). Another study investigated the preferred communication method of patients in a primary care setting. The study concluded that many patients are content with getting results through password-protected portals, which can be preferred over a phone call (Liederman & Morefield, 2003).

Different types of communication have been shown to impact patient's anxiety and understanding of information. To reduce patient's anxiety about test results, they need to be communicated clearly and accurately (Litchfield et al., 2014). A study was conducted in 2019 to understand how altered methods of communication affected patient's anxiety, understanding, and preferences when receiving cancer screening results. This study concluded that contact through direct communication methods were preferred by patients and ultimately resulted in better comprehension of the results. However, the study could not determine which communication technique resulted in less anxiety (Williamson et al., 2019).

Currently, cancer genetic counseling literature emphasizes rising rates of VUS reclassification results and briefly explores patient perspectives when there is a reclassification of their VUS. With improved technology and an increase in referrals for cancer genetic testing, more people are pursuing multi-gene panel tests and thus

increasing the amount of available genetic data. It is relatively common for a panel test to result in a variant of uncertain significance. As more is understood about cancer susceptibility genes, laboratories are able to reclassify previously identified variants to either benign or pathogenic. With every step forward, there remains the question of how best to disclose a reclassified result to a patient. The key element of patient preference for being informed of a change in their test result remains unexamined, resulting in a lack of a standardized method to deliver reclassified VUS results.

There are a number of ways that a patient could be notified of a reclassified VUS result, including a telephone call, an in-person appointment, a secure message on a portal, or a letter by U.S. mail. With many different options to inform patients, there is no standardized communication mode being utilized in the field of genetic counseling. Effective interaction between healthcare providers and patients is primarily dependent upon communication. In order to have successful communication, it is important for healthcare providers to incorporate patient preferences when deciding upon a communication method.

This study was conducted to determine the paramount way for genetic counselors to communicate reclassified test results with patients. This study considered how the mode of communication might change if the VUS was upgraded, if the VUS was downgraded, or if multiple VUS results were identified. This study also investigated patient communication with relatives regarding a VUS result and if the level of concern a patient expresses about their VUS result correlates to a desire for a specific method of communication. The ultimate goal of this study was to make recommendations to cancer

genetic counselors about patients' preferred method for disclosing reclassified VUS results.

We hypothesized that patients' desired form of communication would differ depending on the reclassified result received. We expected patients who have a VUS downgraded would be more comfortable with a less personalized communication method, while a patient with a VUS that is upgraded would prefer a more direct communication method. Lastly, it was predicted that patients with more than one VUS identified may only want to be contacted if one of the results was upgraded to likely pathogenic.

2.3 Methods

2.3.1 Participants and Recruitment

This study was approved by the institutional review board at the University of South Carolina in June of 2020. The primary aim of this research was to assess how patients desired to receive reclassified VUS results from cancer genetic testing. Therefore, participation was limited to Prisma Health Genetic Counseling patients who had a VUS result on a cancer genetic test within the last two years. Individuals were excluded if they already had their VUS result reclassified, had a pathogenic result in addition to the VUS result, are non-English speaking, or are under age 18.

Recruitment for this study was done with the aid of Prisma Health cancer genetic counselors who had records of past patients with a VUS result. An invitation letter was mailed to eligible patients from their genetic counselor (Appendix A). The letter was included in current VUS results sent to patients by the cancer genetic counselors during the data collection period while also being mailed to patients who had cancer genetic

testing with at least one VUS result over the past 2 years. Due to low questionnaire response rates, a second invitation letter was mailed to a subset of the original eligible patients from their genetic counselor (Appendix B).

An anonymous online questionnaire was used in this study. Participation in the questionnaire was voluntary. Participants were informed that they could withdraw from the questionnaire at any time by not completing the questionnaire. Once the participant entered the anonymous link or utilized the QR code in the invitation letter, the questionnaire welcome page detailed the background and purpose of the study, expected duration, eligibility requirements, and information regarding consent (Appendix C). There were multiple screening questions in the questionnaire, and any participant who was not eligible had their data deleted from analysis. A total of 273 individuals were originally contacted to invite them to participate in the online survey. Of the original 273, 100 people were randomly selected using a random number generator to be recontacted to participate in the online survey. A total of 34 participants completed the online questionnaire, and the demographic information can be seen in Table 2.1. Questionnaire responses were recorded from June 25th, 2020 to December 15th, 2020.

Following completion of the questionnaire, participants were shown the closing screen of the questionnaire which included a thank you for their participation and a link to enter a raffle (Appendix E). To incentivize participation, questionnaire participants could enter a raffle to win one of five $20.00 Amazon gift cards. Participants were consented again before entering the raffle (Appendix F). To enter the raffle, participants provided their name and preferred email (Appendix G). Entering in the raffle was optional and the email addresses were not linked to the questionnaire responses. At the

end of the questionnaire response period, five participants were randomly selected using online software.

2.3.2 Instrumentation

The online questionnaire was developed through Qualtrics.com (Appendix D). The questionnaire included items about the patient's VUS result as well as the preferred method of notification if the VUS result was reclassified. The questionnaire had 22 items. There were two questions for participants to rank their preferences regarding communication methods, two free-response question, and 18 multiple choice questions. Skip logic was utilized for participants who answered that they had a single VUS result, so they would not answer questions regarding multiple VUS results. Demographic information questions were placed at the end of the questionnaire to learn participant's age, sex, race, and level of education.

2.3.3 Data Analysis

Qualtrics.com software was utilized to collect participant response from June 25th, 2020 to December 15th, 2020, then participant responses were downloaded for analysis. For quantitative analysis, the data was transferred from Microsoft Excel spreadsheets to Statistical Package for Social Sciences (SPSS). To address the research goal, descriptive statistics, including frequencies and percentages, were calculated. Independent T-Tests were utilized to analyze rank order questions to identify significant differences between patient's communication preference for an upgraded VUS and a downgraded VUS result. Chi-squared Tests for Independence were used to analyze associations between various categorical variables. The qualitative responses produced from free response questions were utilized to enhance data from the quantitative analysis.

2.4 Results

2.4.1 Communication Method Preferences for Upgraded Versus Downgraded

Of the 34 participants, 47.06% ranked telephone call by a genetic counselor as their most preferred communication method for an upgraded VUS result. Alternatively, 50.00% (n = 34) of participants ranked letter in mail as their most preferred communication preference for a downgraded VUS results (Figure 2.1).

The majority of participants ranked telephone call by a genetic counselor (47.06%) as the most preferred method of communication for an upgraded VUS result. The ranking system went to six, but if a participant left it blank then that was automatically the sixth choice (least preferred). The majority of participants (79.41%) left the sixth choice blank. The least preferred communication method that was selected for an upgraded VUS result was secure web-portal (35.29%) (Table 2.2).

Half of participants ranked letter in the mail (50.00%) as their most preferred method of communication for a downgraded VUS result. Again, the majority of participants (79.41%) left the sixth choice blank. The least preferred communication method that was selected for a downgraded VUS result was an in-person appointment with a genetic counselor (38.24%) (Table 2.3).

Participants were assessed on which communication method they would not want utilized for notification of an upgraded VUS. In total, 47.06% of participants did not specify a communication method for this item. Of the participants who expressed a preference, the most selected answer (20.59%) was a secure web-portal notification (Figure 2.2). Additionally, participants were assessed on which communication method they would not want utilized for notification of a downgraded VUS result. In total, a

majority of participants (58.82%) did not specify a communication method for this item. Of the participants who expressed a preference, the most selected answers were an in-person appointment with a genetic counselor (17.65%) and a secure web-portal notification (17.65%) (Figure 2.3).

2.4.2 Communication Method Preferences for Multiple VUS Results

Of the 34 participants who completed the survey, 19 (55.88%) reported having two or more VUS results. Of the 19 participants with multiple VUS results, 17 (89.47%) reported wanting to be contacted each time a VUS is changed, and 2 (10.53%) reported wanting to be notified only when all VUS results were changed (Figure 2.4).

The 19 participants with multiple VUS results were asked about their most and least preferred communication method for being told of a single downgraded VUS result. One participant did not make a selection for this item. Of the 18 who responded to this item, half (50.00%) marked telephone call by a genetic counselor as their most preferred communication method. All 19 participants selected their least preferred communication method which was most often an in-person appointment with a genetic counselor (36.84%) (Figure 2.5).

The 19 participants with multiple VUS results were questioned regarding their most and least preferred communication method for being told that all of their VUS results were reclassified. Of these participants, 18 selected their most preferred communication method. The majority of participants (61.11%) selected a telephone call by a genetic counselor as their most preferred communication method for all VUS results being reclassified. All 19 participants selected their least preferred communication method which was most often a letter in the mail (36.84%) (Figure 2.6).

When comparing the most preferred and least preferred method of communication, there was no statistical difference in mean between most and least preferred method of communication for only one VUS result being reclassified (M= -0.63, SD=2.01, $t(18)$=1.37, p=0.19). Additionally, there was no statistical difference in mean between most and least preferred method of communication for all VUS results being reclassified (M= -0.63, SD=1.98, $t(18)$=1.39, p=0.18).

2.4.3 Level of Concern Regarding VUS Result

Of the 34 participants who took the survey, 64.71% reported having a personal history of cancer. A majority of participants (59.09%) reported a personal history of breast and/or ovarian cancer (Figure 2.7). Of all participants, 91.18% reported having a family history of cancer. The majority of participants (61.29%) with a family history of cancer reported having multiple types of cancer in the family (Figure 2.8).

The participants were queried on their level of concern about the VUS finding, and all 34 participants reported their level of concern. A majority of participants (55.88%) reported being "mildly concerned" (Table 2.4). Regarding how often participants think of their VUS result, 44.12% reported they rarely think about their VUS result (Figure 2.9). Concerned participants noted that they were "concerned because it's a mutation but not enough is known", that "the unknown is troubling", and there is "… the possibility of [their] children inheriting the VUS". A moderately concerned participant shared that to them, "no news is good news…". Participants who reported being mildly concerned testified that they "rarely think about it", are "mildly concerned when reminded of the variant", and they "…would only think about it and be concerned if it [was] upgraded". Participants who noted that they were not concerned made statements

including “I [was] the first family member to complete genetic testing, [and] doubt others will” and that “it's hard to understand what exactly all of it means, so to me, my Dr will advise me if I should worry”.

2.4.4 Patient Communication of VUS Result

Of the 34 participants, 33 participants disclosed if they discussed their VUS result with their family members. A majority of the participants (72.73%) reported sharing their VUS result with their family. All 33 respondents reported that they would tell their family if their VUS result was upgraded and 84.85% reported that they would tell their family if their VUS result was downgraded. Of the 34 participants, 33 reported on the amount of information they received at the time of receiving their VUS result. A majority of participants (84.85%) reported that they received the right amount of information when receiving their VUS result, while 15.15% reported wanting more information when receiving their VUS result.

2.5 Discussion

2.5.1 Communication Method Preferences for Upgraded Versus Downgraded

While there is previous literature that investigated patient’s desired communication method when receiving initial test results, there is no apparent literature published that explores patient communication preferences for a reclassified VUS result. Since this has never been investigated, there are currently no standard guidelines for the healthcare field regarding the delivery of reclassified VUS results to patients (Halverson et al., 2019). To attempt to address this, rank order items were utilized for communication method rating because it highlights which communication methods are regarded as more or less favorable. Results of this study identified that the most preferred communication

method for an upgraded result differed from the most preferred communication method for a downgraded result.

For an upgraded VUS result, participants desired a more direct communication method through a telephone call by a genetic counselor. Alternatively, participants desired a less direct communication method through a letter in the mail for a downgraded VUS result. An upgraded VUS result may have clinical management recommendations for a patient and family cascade testing that could require a more in-depth explanation for a patient, which could be conveyed better through a phone call (Halverson, 2019; Halverson et al., 2020). Interestingly, participants consistently ranked secure web-portal and in-person appointment with a genetic counselor as their two least preferred methods of communication for both upgraded and downgraded results. This suggests that in either situation, those would not be a desired communication method for being informed of a VUS reclassification. This finding differs from past research, including Liederman and Morefield (2003), who determined that patients were comfortable receiving results through patient portals, and sometimes patient portals were preferred over a phone call. However, secure web-portals limit a patient's ability to ask questions pertaining to a reclassification, which could be a reason that participants did not prefer a secure web-portal. Studies previously showed that sharing results from a cancer susceptibility genetic test had the same impact when delivered in person or over the phone (Jenkins et al., 2007; Platten et al., 2012). Participants preferred communication through a phone call compared to in-person, which could be due to convenience of a phone call that still offers direct communication, no wait or travel time for an appointment, and gives patients the ability to have questions answered immediately regarding results. While participants did

rank a top choice for an upgraded result and a downgraded result, there was no well-defined order of preferred communication methods for this small sample size. This could be due to participants having no strong preference of communication.

Most participants did not specify a communication method they would not want utilized for either an upgraded VUS or a downgraded VUS, which suggests that patients are open to a variety of communication methods. However, when participants did express a communication method that they would not want utilized, it was primarily secure web-portal and in-person appointment with a genetic counselor. Again, this could be because a secure web-portal does not give patients the ability to ask questions directly to a healthcare provider and can be a barrier for people who do not have access to a computer or internet. Participants could perceive several disadvantages regarding an in-person appointment, such as the travel time and inconvenience of a genetic counseling appointment. This may include travel expenses, taking time off work, and the price of the appointment. Participants ranked speaking with a genetic counselor via telephone as a top choice for both upgraded and downgraded VUS results, so the selection of an in-person appointment with a genetic counselor is likely not due to the actual communication with a genetic counselor. Platten, et al. (2012) identified high satisfaction rates regarding cancer counseling conducted by telephone and in-person, and they suggested that the telephone model could be an equal or better alternative to in-person counseling, which is reflected from the participants' rank order preferences in this study. This is also supportive of cancer genetics clinics being able to establish a standard protocol that works best for them, as some of these methods require greater time and effort from the clinic.

2.5.2 Communication Method Preferences for Multiple VUS Results

More than half of the initial participants who completed the questionnaire had multiple VUS results. We explored timing of when participants desired to be notified regarding a VUS reclassification and found that a majority of participants wanted to be contacted each time a VUS was changed, even if it would not result in altered management or have family testing implications. This could be because learning about one reclassification reduces the amount of uncertainty participants with multiple VUS results are experiencing. Additionally, we investigated how multiple VUS results would affect a participant's preferred communication method regarding a single downgraded VUS result. Ultimately, participants claimed to want a telephone call by a genetic counselor for only one downgraded VUS result. This result was discordant with the initial information gathered when looking at everyone who participated. When asking about preferences, in general, participants selected letter in the mail as the most preferred method of communication for a downgraded result. However, when focusing on their specific finding of multiple VUS results, participants with multiple VUS results desired a telephone call by a genetic counselor. This result highlighted an inconsistency between patient preference of our entire cohort compared to those that received a result with multiple VUS. This is likely due to the fact that they may have more questions regarding their other remaining VUS results that may not be answered in a letter. Alternatively, participants with multiple VUS results least preferred method of communication for only one VUS result being downgraded was an in-person appointment with a genetic counselor, which was consistent with the initial information gathered. We believe that patients may consider the ability to ask questions and amount of information that they

receive over the phone as the same as going to an in-person appointment without the additional inconvenience of an in-person appointment.

Similarly, participants selected a telephone call by a genetic counselor as their top communication method preference for all VUS results being reclassified. This is a more complex result, which may lead to additional questions, leading patients to prefer a more direct communication method to learn of all their VUS results being reclassified. Having a telephone call by a genetic counselor selected as the top preference many times shows the importance of direct communication with a genetic counselor in disclosing and explaining genetic test results to patients. The finding of a letter in the mail being least preferred as a method of communication of all VUS results being downgraded may be due to the indirect nature of the communication method. A letter in the mail forces the patient to call with any questions. This is consistent with results of the 2019 study by Williamson et al., which assessed how different communication techniques used for cancer results influences a patient's understanding and anxiety. Similarly, our study showed that communication through direct methods (i.e., telephone or in person) were preferred and could lead to better understanding of the results compared to the less direct methods of communication (i.e., letter in the mail).

2.5.3 Level of Concern Regarding VUS Result

According to Litchfield et al. (2014), communication of test results is complex and healthcare workers should take patient's anxiety levels into consideration for the communication method chosen to explain test results. In this study, we examined patient's reported level of concern and how often they think about their VUS result. Patients expressed differing levels of concern regarding their uncertain results. Most of

the participants expressed mild concern regarding their VUS result and would "rarely think about it." One participant expressed that they are "mildly concerned when [they are] reminded of the variant." When explaining a reclassified variant, it would be important to remind the patient of their initial testing and result because significant time may have passed, and patients may not recall all the information regarding their initial result. This is supported in this study by most patients reporting rarely thinking about their result and having only mild concern regarding their result. A participant who reported being concerned expressed that "the unknown is troubling," so describing the details of a reclassified VUS result could help ease some of the concern regarding the unknown. A VUS result that is reclassified to "likely pathogenic" or "pathogenic" impacts the patient and their family, so it is important to consider how patients feel about the VUS for themselves and their family and the impact the reclassification may have. Participants conveyed concern with regards to the "possibility of [their] children inheriting the VUS…" which demonstrates that they understand the inheritance pattern and that a VUS could impact their family members. Since most participants shared that they were mildly concerned regarding their VUS result and that they rarely think about it, a genetic counselor's preference for communication method may not be impacted by a patient's level of anxiety regarding an uncertain result. However, it could be important to consider how an upgraded result could cause anxiety and select a more direct communication method to be able to share the result and be able to answer the patient's questions.

2.5.4 Patient Communication of VUS Result

When someone is found to have a VUS result, it is not typically recommended that other family members undergo genetic testing for the specific variant (Gradishar et al., 2020). In this study, most participants reported that they discussed their VUS result with family members. All participants who responded stated that they would share an upgraded VUS result with their family and a majority indicated they would tell their family about a downgraded VUS result. These responses suggest that participants understand that sharing this information allows family members to have reassurance about the uncertain result and confirms that they do not need to undergo genetic testing for the specific variant. A potential reason behind all participants stating that they would share an upgraded result is due to their understanding that an upgraded result could lead to family cascade testing and have implications for their family members' healthcare (Halverson, 2019; Halverson et al., 2020).

2.6 Limitations and Future Research

This study had several limitations. The conclusions able to be drawn from this research are limited because the responses from participants were voluntary. The participant sample was biased, since all of the patients were recruited from Prisma Health cancer genetic counseling. Another limitation of this study was the low response rate among the patients who were mailed letters resulting in a small sample size. Due to the low response rate, no generalized recommendations could be made for a standardized guideline for genetic counselors to utilize when informing patients of a reclassified VUS result. Additionally, recall bias may have influenced participants' responses since some may have received their VUS result as long as two years ago. Though the majority of

participants received their VUS result within the last year, their understanding of the result and implications of a reclassification may have changed overtime. While rank order items allowed participants to list preferences of communication methods, it is a stringent technique. Participants may not have a preference between two communication methods but would have had to rank a preference.

Future studies could explore the perspectives of patients from other healthcare systems to get a larger sample and more generalizable data. A number of participants would not want to be seen in-person regarding a reclassified VUS result, even when the result is upgraded, which could partially be due to barriers to genetic counseling. Future studies could assess if the participants' rank order would change with the addition of telemedicine as an option for receiving a VUS result reclassification. Additionally, future studies may want to include additional qualitative questions to learn why participants ranked communication methods the way that they did. This study looked at a hypothetical situation of a VUS result being reclassified, so future studies could compare answers between a group of patients who have had a VUS reclassified already versus a hypothetical VUS reclassification. As more patients undergo a VUS reclassification, it may be beneficial to investigate how different genetic counselors, genetic professionals, and other healthcare providers discuss this information with patients.

Overall, recommending guidelines for healthcare providers regarding communication methods for reclassified VUS results was not achievable because there was no clear participant preference. However, important factors to consider for genetic counselors to consider include patient anxiety, patient preferences, and the specific variant reclassification. Cancer genetic counselors could consider discussing

communication method preferences with their patients during the appointment to establish a personalized way to recontact each patient.

Table 2.1 Participants demographic information

Category	Responses	Total (*n*)	Percent (%)
Age Group (*N*=29)	20-30	2	6.90%
	30-40	3	10.34%
	40-50	8	27.59%
	50-60	8	27.59%
	60-70	7	24.14%
	70+	2	3.45%
Sex (*N*=33)	Female	31	93.94%
	Male	2	6.06%
Race/Ethnicity (*N*=33)	White/Caucasian	28	84.85%
	Black/African American/ African	2	6.06%
	American Indian or Alaska Native	0	0.00%
	Spanish/Hispanic/Latino	2	6.06%
	Asian Indian	0	0.00%
	Chinese	1	3.03%
	Japanese	0	0.00%
	Other Asian	0	0.00%
	Native Hawaiian or Pacific Islander	0	0.00%

Highest Level of Education (*N*=32)	No education	0	0.00%
	Middle school	0	0.00%
	Some high school	0	0.00%
	High school graduate	1	3.03%
	Some college	8	24.24%
	Associate degree	4	12.12%
	Bachelor's degree	12	36.36%
	Master's degree	6	18.18%
	Professional degree	1	3.03%
	Doctorate degree	1	3.03%
Informed of VUS result	1-6 months ago	10	30.30%
	7-12 months ago	11	33.33%
	12-18 months ago	11	33.33%
	19-24 months ago	2	6.06%

Table 2.2 Number of participants who ranked each method of communication for UPGRADED (1= most preferred; 6= least preferred)

	One	**Two**	**Three**	**Four**	**Five**	**Six**
Letter in the mail	9	8	7	5	5	0
Telephone call by a genetic counselor	16	14	3	0	1	0
Telephone call by medical assistant	3	8	11	7	4	1

In-person appointment with a genetic counselor	3	2	7	11	8	3
Secure web-portal	1	1	6	11	12	3
Other	2	1	0	0	4	27

Table 2.3 Number of participants who ranked each method of communication for DOWNGRADED (1= most preferred; 6= least preferred)

	One	Two	Three	Four	Five	Six
Letter in the mail	17	5	5	2	3	0
Telephone call by a genetic counselor	10	14	7	0	1	0
Telephone call by medical assistant	1	11	12	8	0	0
In-person appointment with a genetic counselor	0	0	4	13	13	2
Secure web-portal	3	2	4	8	12	3
Other	1	0	0	1	3	27

Table 2.4 Participant's level of concern regarding their VUS result

Level of concern	Number of Participants (*n*)	Percent (%)
Not concerned	5	14.71%
Mildly concerned	19	55.88%
Moderately concerned	4	11.76%
Concerned	6	17.65%

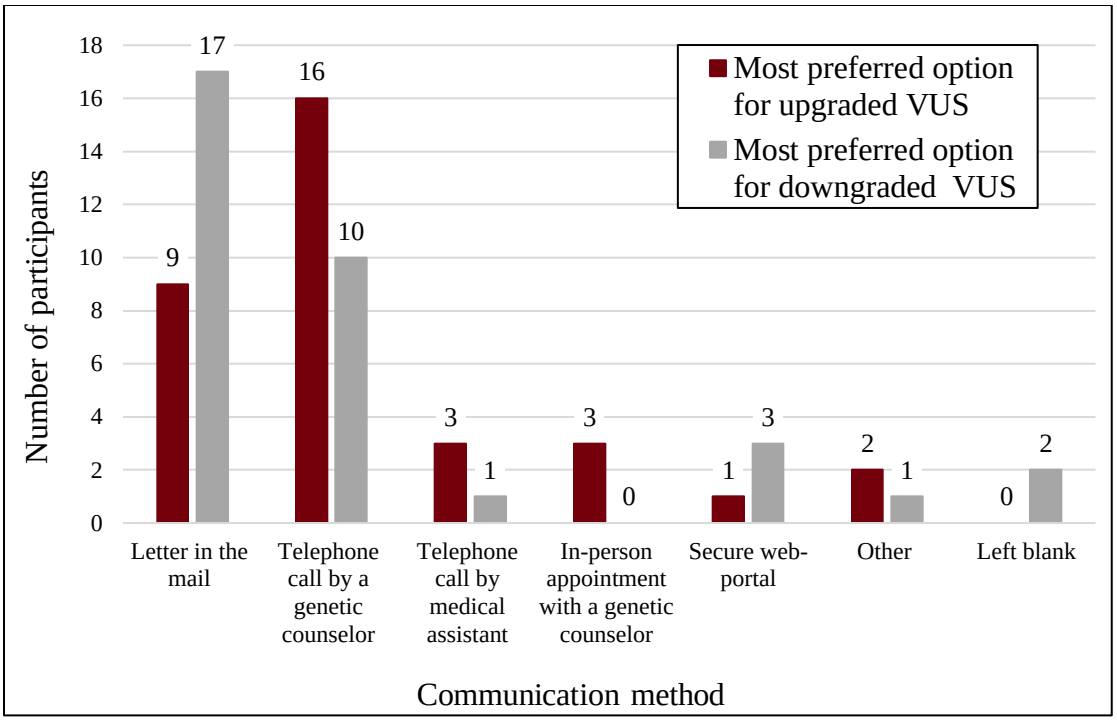

Figure 2.1 Most preferred communication method for upgraded vs downgraded VUS result

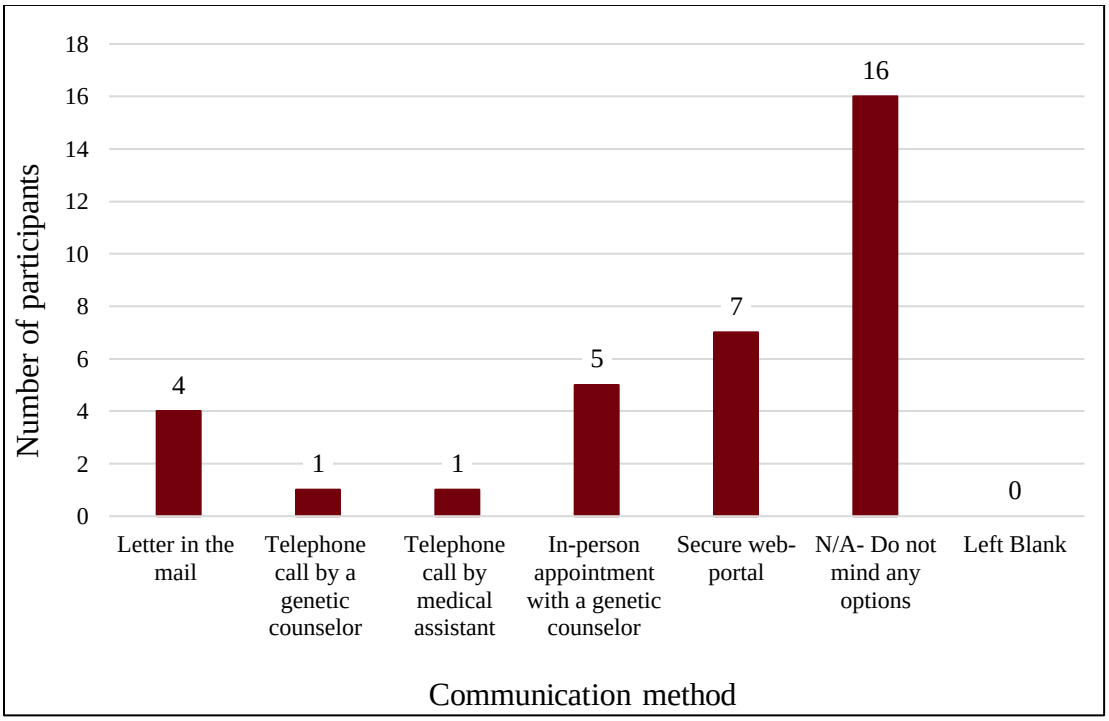

Figure 2.2 Number of participants who would NOT want a specific communication method for notification of VUS being UPGRADED

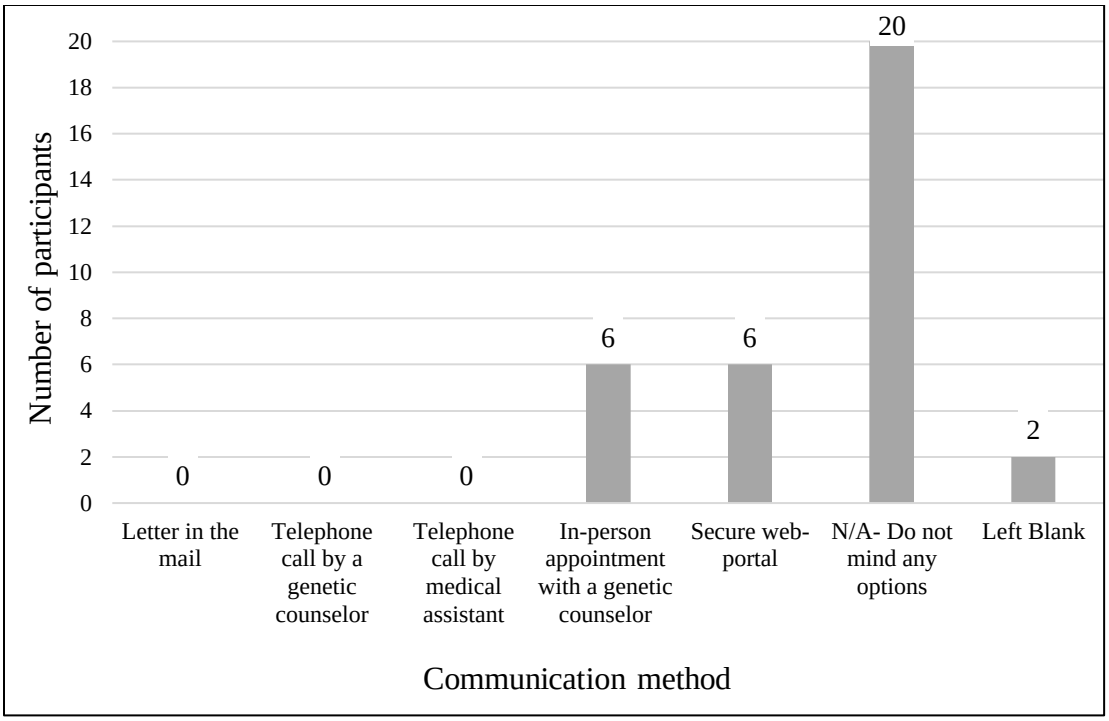

Figure 2.3 Number of participants who would NOT want a specific communication method for notification of VUS being DOWNGRADED

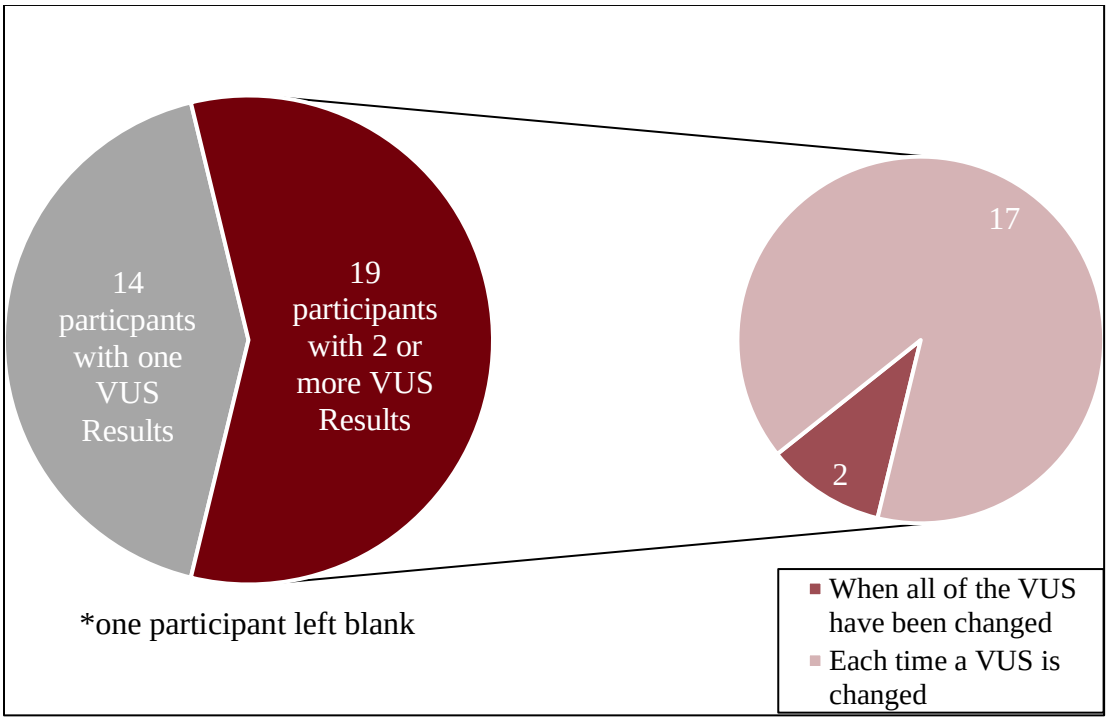

Figure 2.4 Notification Preferences with Multiple VUS Result

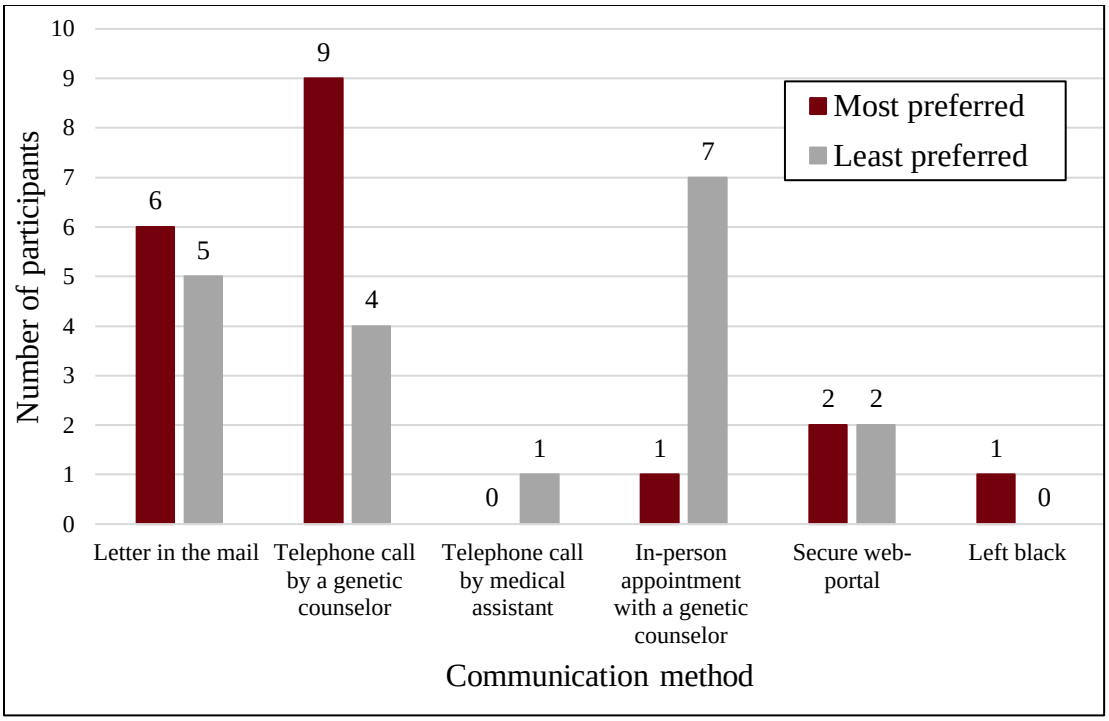

Figure 2.5 Communication preference for multiple VUS results with one being downgraded

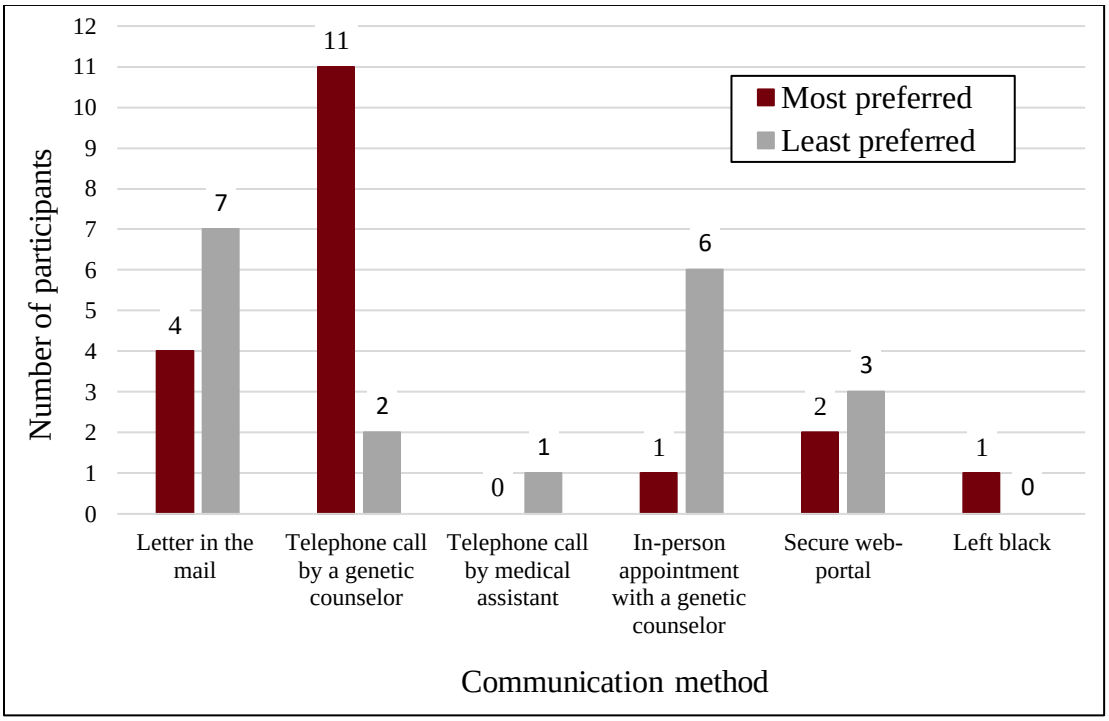

Figure 2.6 Communication preference for multiple VUS results with all being reclassified

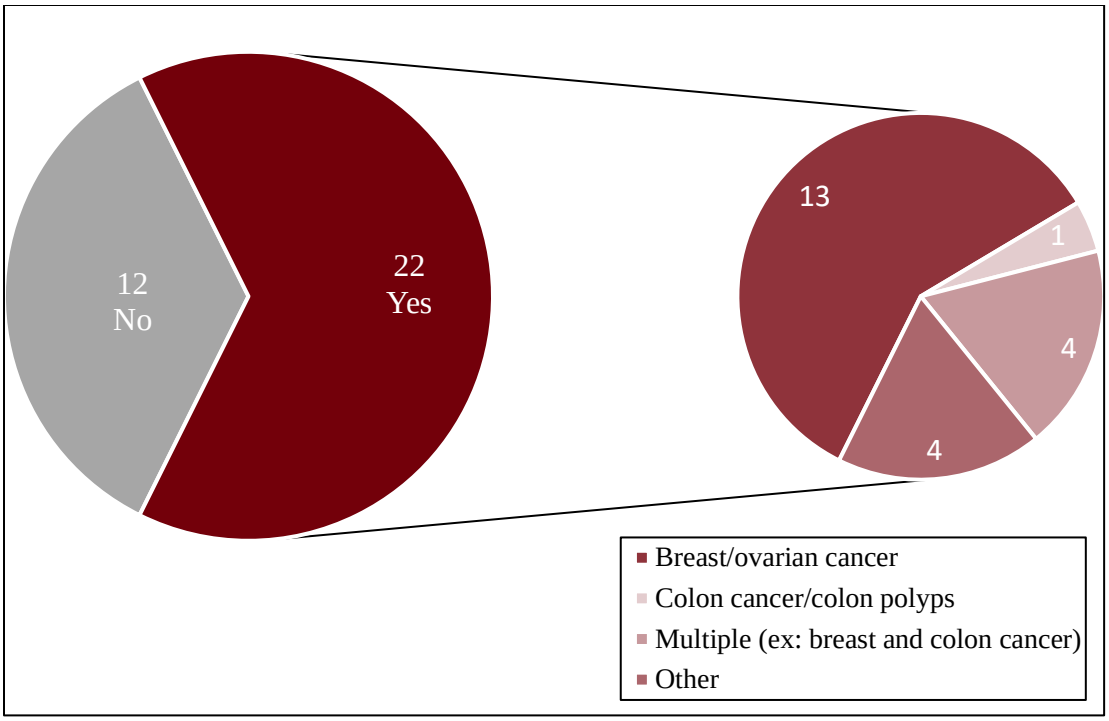

Figure 2.7 Personal history of cancer

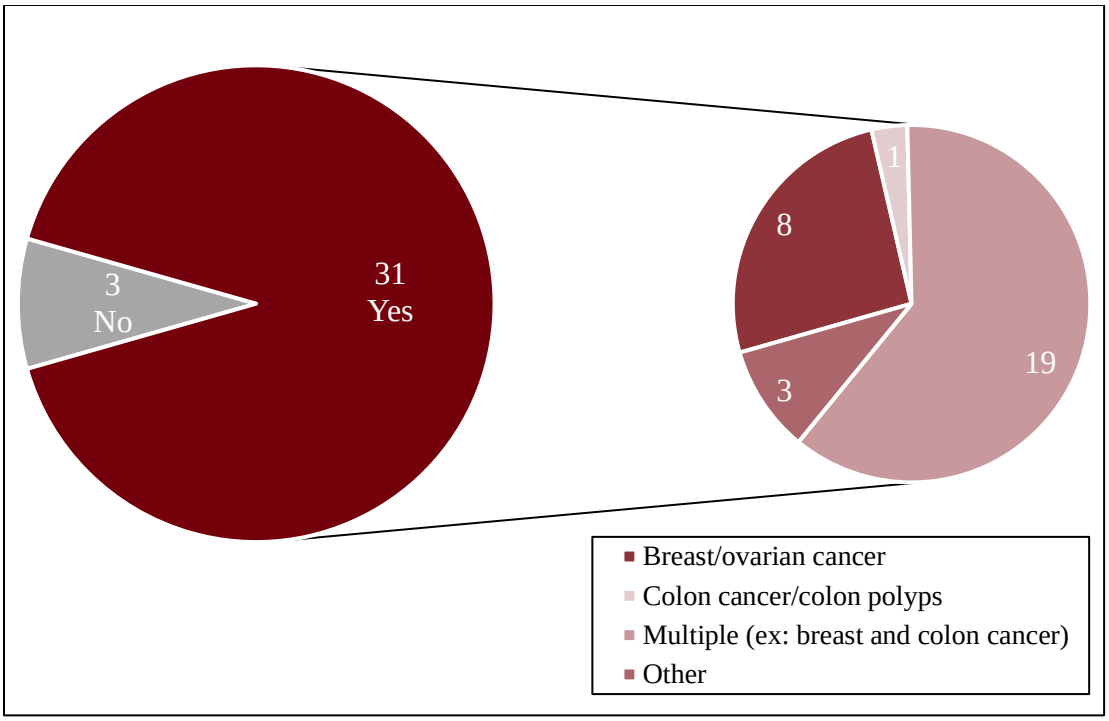

Figure 2.8 Family history of cancer

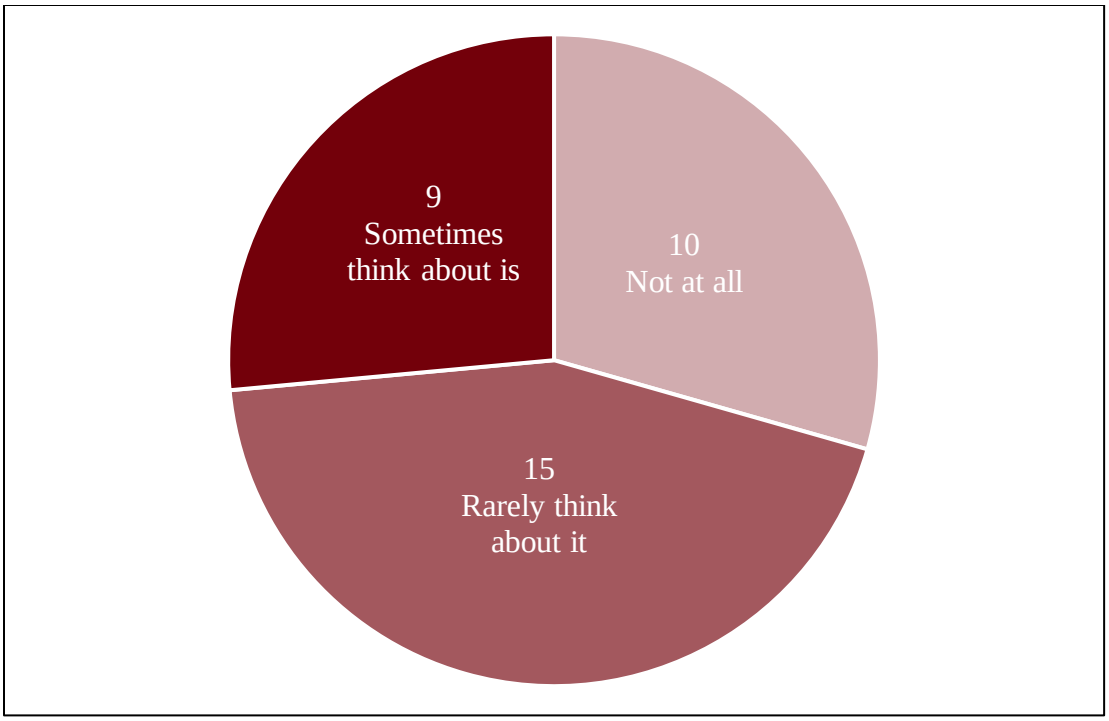

Figure 2.9 How often participant's report thinking about their VUS result

CHAPTER 3

CONCLUSIONS

Cancer genetic counseling services are available for patients with personal and or family history that is suspicious of a hereditary cause of cancer. Genetic testing allows patients to understand their inherited cancer risk. As more people undergo genetic testing, there is a higher diagnostic yield overall along with more uncertain results. However, as technology improves and more is learned about cancer predisposition genes, there is a higher chance for variant reclassification to occur. Cancer genetic counselors should be aware of an increased rate of reclassified VUS results and consider how they desire to update patients regarding this information. There is no standard guideline for healthcare providers of how to deliver reclassified VUS results. Knowing how patient communication preferences differ based on if the VUS was upgraded, if the VUS was downgraded, or the number of VUS results are important factors to consider when determining a standardized method for result disclosure of a reclassified VUS result. Considering the present data, it was not possible to make definitive recommendations for healthcare providers regarding delivery of reclassified VUS results. Since the participants did not have a strong preference, healthcare providers can consider using a communication method that is best for their clinic based on the capabilities including time and resources. Findings from this study can inform genetic counselors that patient preferences, patient anxiety, and type of variant reclassification are all factors that can change the method of communication used to disclose a reclassified VUS result.

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APPENDIX A

INITIATIAL PARTICIPANT RECRUITMENT LETTER

Dear Patient,

I am writing to invite you to participate in a University of South Carolina Master in Genetic Counseling student thesis project. Cooper Hall is working towards completing her master's degree and is conducting research to learn how patients would like to be notified if their uncertain cancer genetic results are updated by the genetic testing laboratory.

You are receiving this letter because you underwent cancer genetic counseling and your test results revealed a variant of uncertain significance (VUS). A VUS means that there is a change in one of your genes, but we do not know if this change is harmful (also called a positive) or normal (also called negative). The goal of this research project is to understand how patients prefer to receive updated information if their variant of uncertain significance (VUS) test result is reclassified to either positive or negative. We aim to utilize the information learned in this study to help healthcare providers deliver better quality care for their patients.

The survey will ask you to rate how you would prefer to be notified if your VUS result is updated and will also include questions about your VUS result and demographic information. **You may find it beneficial to have a copy of your genetic test results available for you to look at while you take this survey.** Participation in this study involves the completion of an online survey that will be available until December 15th at midnight. The survey will be available online through Qualtrics and should take no more than 15 minutes to complete. Participation in this study is voluntary. You are giving consent for your participation in this study by finishing and submitting the online survey. At any time during the survey, you may exit and not complete the survey. All responses from the survey will be anonymous and no identifying information will be recorded. If you complete this survey, you may choose to enter a raffle for a chance to win **one of five $20.00 gift cards for Amazon**.

If you are interested in taking this survey, please enter the following link into your internet browser on your computer, smart phone, or tablet, or scan the QR link.
Link: https://uofsc.co1.qualtrics.com/jfe/form/SV_eWXZ79ZKa1Nh5op

Thank you for your consideration to participate in this study. Your involvement is exceedingly valuable as it will help healthcare providers better communicate updated genetic test results with patients that have received a VUS result. If you have any questions or trouble with the online survey, please reach out to myself or Cooper Hall, the primary investigator.

Sincerely,

Counselor name
Ph: XXX-XXX-XXXX

Cooper N. Hall, BS
Ph: XXX-XXX-XXXX
Email: cooper.hall@uscmed.sc.edu

APPENDIX B

PARTICIPANT SECOND RECRUITMENT LETTER

Survey deadline extension to Dec 15th, 2020 at Midnight. If you have already completed the survey, please disregard this letter.

Dear Patient,

I am writing to invite you to participate in a University of South Carolina Master in Genetic Counseling student thesis project. Cooper Hall is working towards completing her master's degree and is conducting research to learn how patients would like to be notified if their uncertain cancer genetic results are updated by the genetic testing laboratory.

You are receiving this letter because you underwent cancer genetic counseling and your test results revealed a variant of uncertain significance (VUS). A VUS means that there is a change in one of your genes, but we do not know if this change is harmful (also called a positive) or normal (also called negative). The goal of this research project is to understand how patients prefer to receive updated information if their variant of uncertain significance (VUS) test result is reclassified to either positive or negative. We aim to utilize the information learned in this study to help healthcare providers deliver better quality care for their patients.

The survey will ask you to rate how you would prefer to be notified if your VUS result is updated and will also include questions about your VUS result and demographic information. **You may find it beneficial to have a copy of your genetic test results available for you to look at while you take this survey.** Participation in this study involves the completion of an online survey that has been extended to December 15th at midnight. If you have already taken the survey, please ignore this letter, and do not take the survey again. The survey will be available online through Qualtrics and should take no more than 15 minutes to complete. Participation in this study is voluntary. You are giving consent for your participation in this study by finishing and submitting the online survey. At any time during the survey, you may exit and not complete the survey. All responses from the survey will be anonymous and no identifying information will be recorded. If you complete this survey, you may choose to enter a raffle for a chance to win **one of five $20.00 gift cards for Amazon**.

If you are interested in taking this survey, please enter the following link into your internet browser on your computer, smart phone, or tablet, or scan the QR link.
Link: https://uofsc.co1.qualtrics.com/jfe/form/SV_eWXZ79ZKa1Nh5op

Thank you for your consideration to participate in this study. Your involvement is exceedingly valuable as it will help healthcare providers better communicate updated genetic test results with patients that have received a VUS result. If you have any questions or trouble with the online survey, please reach out to myself or Cooper Hall, the primary investigator.

Sincerely,

Counselor name
Ph: XXX-XXX-XXXX

Cooper N. Hall, BS
Ph: XXX-XXX-XXXX
Email: cooper.hall@uscmed.sc.edu

APPENDIX C

PARTICIPANT ONLINE QUESTIONNAIRE INTRODUCTION

Thank you for your interest in participating in my master's research project. Please review the study details below prior to completing this survey.

PURPOSE AND BACKGROUND:
You are being asked to participate in a research study conducted by Cooper Hall, a Master of Science in Genetic Counseling Student at University of South Carolina. This study aims to assess how patients wish to receive news of an amended variant of uncertain significance result. You are being asked to participate in this survey because your genetic test results revealed a variant of uncertain significance (VUS) identified on cancer genetic testing. A VUS means there is a change in one of your genes, but we do not know if this change is a harmful (also called pathogenic/mutation) or normal (also called benign/negative).

You may find it beneficial to have a copy of your genetic test results available to look at while you take this survey.

DURATION:
Participation in this survey should take no more than 15 minutes

PARTICIPATION:
Participation in this study is voluntary. You may choose to exit the survey at any time. You may skip individual questions in the survey that you are uncomfortable answering. All answers collected in the survey will remain anonymous and confidential. The data will be stored in a secure device and can only be viewed by the primary investigator. In the event that you withdraw participation in this study, the information provided will be kept in a confidential manner and discarded at the conclusion of the study.

PAYMENT:
We thank you for your interest, time, and participation in this survey. If you complete this survey, there will be a final optional question where you can be entered into a raffle for **a $20.00 gift card to Amazon**. If you select "Yes" at the end of the survey, then it will redirect you to a new survey to enter your name and email address for the chance to win a $20.00 gift card to Amazon. This information will **not** be linked back to your survey response.

CONSENT:
By completing this survey, you are consenting for your data to be used in this study and any future research, presentations, or publications related to this project.

If you have any questions, please contact Cooper Hall, by email (cooper.hall@uscmed.sc.edu) or phone (714-624-0111).

By clicking the blue arrow, you agree to participate in this survey.

APPENDIX D

ONLINE QUALTRICS QUESTIONNAIRE FOR PARTICIPANTS

1. **Question**: When were you informed that you have a Variant of Uncertain Significance?
    - 1-6 months ago
    - 7-12 months ago
    - 13-18 months ago
    - 19-24 months ago
2. **Question:** How would you prefer to be notified if your Variant of Uncertain Significance (VUS) was reclassified from VUS to **harmful or likely harmful** (**UPGRADED**)? Please drag and drop the following options so that 1 is the way you would **most** prefer to be notified and 6 is the way you would **least** prefer to be notified. **(1 most preferred; 6= least preferred)**
    - _____ Letter in the mail
    - _____ Telephone call by a genetic counselor
    - _____ Telephone call by medical assistant (or other healthcare provider)
    - _____ In-person appointment with a genetic counselor
    - _____ Secure web-portal
    - _____ Other (Please specify)
3. **Question:** Are there any methods that you would **NOT** like to be used to notify you if your VUS was **UPGRADED**? Select all that apply.
    - Letter in the mail
    - Telephone call by a genetic counselor
    - Telephone call by medical assistant (or other healthcare provider)
    - In-person appointment with a genetic counselor
    - Secure web-portal
    - Other (Please specify)
4. **Question:** How would you prefer to be notified if your Variant of Uncertain Significance (VUS) was reclassified from VUS to **normal** (**DOWNGRADED**)? Please drag and drop the following options so that 1 is your **most** preferred way you would like to be notified ant 6 is your **least** preferred way you would like to be notified. **(1 most preferred; 6= least preferred)**

- _____ Letter in the mail
- _____ Telephone call by a genetic counselor
- _____ Telephone call by medical assistant (or other healthcare provider)
- _____ In-person appointment with a genetic counselor
- _____ Secure web-portal
- _____ Other (Please specify)

5. **Question:** Are there any methods that you would **NOT** like to be used to notify you if your VUS was **DOWNGRADED**? Select all that apply
   - Letter in the mail
   - Telephone call by a genetic counselor
   - Telephone call by medical assistant (or other healthcare provider)
   - In-person appointment with a genetic counselor
   - Secure web-portal
   - Other (Please specify)
6. **Question:** If you have more than one Variant of Uncertain Significance, would you prefer to be notified **once** when all of the VUS have been changed or would you prefer to be notified **each time** a VUS is changed?
   - When all of the VUS have been changed
   - Each time a VUS is changed
   - I only had one VUS
7. **Question:** If you had multiple VUS on your genetic test results but **only one** has been reclassified from **VUS to normal**, which of the following would be your **most** preferred method of notification?
   - Letter in the mail
   - Telephone call by a genetic counselor
   - Telephone call by medical assistant (or other healthcare provider)
   - In-person appointment with a genetic counselor
   - Secure web-portal
   - Other (Please specify)
8. **Question:** If you had multiple VUS on your genetic test results but **only one** has been reclassified from **VUS to normal**, which of the following would be your **least** preferred method of notification?
   - Letter in the mail
   - Telephone call by a genetic counselor
   - Telephone call by medical assistant (or other healthcare provider)
   - In-person appointment with a genetic counselor
   - Secure web-portal
   - Other (Please specify)

9. **Question:** If you had multiple VUS on your genetic test results and **all** were reclassified, which of the following would be your **most** preferred method of notification?
    - Letter in the mail
    - Telephone call by a genetic counselor
    - Telephone call by medical assistant (or other healthcare provider)
    - In-person appointment with a genetic counselor
    - Secure web-portal
    - Other (Please specify)
10. **Question:** If you had multiple VUS on your genetic test results and **all** were reclassified, which of the following would be your **least** preferred method of notification?
    - Letter in the mail
    - Telephone call by a genetic counselor
    - Telephone call by medical assistant (or other healthcare provider)
    - In-person appointment with a genetic counselor
    - Secure web-portal
    - Other (Please specify)
11. **Question:** Generally speaking, how concerned are you with your Variant of Uncertain Significance genetic test result?
    - Not concerned
    - Mildly concerned
    - Moderately concerned
    - Concerned
    - Severely Concerned
12. **Question:** How often do you think about your VUS genetic test result?
    - Not at all
    - Rarely think about it
    - Sometimes think about it
    - Think about it frequently
13. **Question:** Please explain why you selected your answers above
14. **Question:** Do you have a personal history of cancer?
    - Yes
    - No
15. **Question:** Please select which indication closely aligns with your history (select all that apply)
    - Breast/ovarian cancer
    - Colon cancer/colon polyps
    - Endocrine tumors/cancer (such as thyroid cancer, parathyroid, pheochromocytoma)

- Colon cancer/ endometrial cancer
- Other (Please specify)

16. **Question:** Do you have a family history of cancer?
    - Yes
    - No
17. **Question:** Please select which indication closely aligns with your history (select all that apply)
    - Breast/ovarian cancer
    - Colon cancer/colon polyps
    - Endocrine tumors/cancer (such as thyroid cancer, parathyroid, pheochromocytoma)
    - Colon cancer/ endometrial cancer
    - Other (Please specify)
18. **Question:** If you have a copy of your genetic test report available, please review and list the gene(s) that had a VUS (e.g.: BRCA1, BRCA2, ATM, TP53, APC). If unsure write "NA"
19. **Question**: Have you discussed your VUS result with any of your family members?
    - Yes
    - No
20. **Question:** Will you tell your family if your VUS result was **UPGRADED**?
    - Yes
    - No
21. **Question:** Will you tell your family if your VUS result was **DOWNGRADED**?
    - Yes
    - No
22. **Question:** Would you have preferred more or less information when you first received your VUS result?
    - I would have liked to have had a longer/more detailed discussion
    - I would have liked to have less details
    - The amount of information was just right

DEMOGRAPHIC INFORMATION

1. **Question:** Your current age (in years)
2. **Question:** Sex
    - Male
    - Female
    - Other
    - Prefer not to answer
3. **Question:** Race/ Ethnicity
    - White/Caucasian
    - Black/African American/ African

- American Indian or Alaska Native
- Spanish/Hispanic/Latino
- Asian Indian
- Chinese
- Japanese
- Other Asian
- Native Hawaiian or Pacific Islander
- Other ethnicity (Please specify)

4. **Question:** Highest Level of Education
    - No education
    - Middle school
    - Some high school
    - High school graduate (e.g., Diploma or GED)
    - Some college
    - Associate degree (e.g., AA, AS)
    - Bachelor's degree (e.g., BS, BA)
    - Master's degree (e.g., MA, MS, MBA)
    - Professional degree (e.g., MD, DDS, DVM, LLB, JD)
    - Doctorate degree (e.g., PhD)
    - Other (Please specify)

APPENDIX E

PARTIPANT ONLINE QUESTIONNAIRE THANK YOU PAGE

Thank you for taking the time to complete our survey. Your participation is greatly appreciated. This study will be valuable for healthcare providers to gain insight into how patients wish to receive reclassified test results so that they can offer the best care to patients.

You have reached the end of the survey, but you have not officially submitted your responses yet.

If you would like to be entered into a raffle drawing for one of five $20.00 Amazon gift cards, please copy the link below into a new browser window to enter your name and email address. Please do so BEFORE submitting your survey, as the link will not be available to you after closing this page.

By filling out the following survey you will be entered into the raffle.

https://uofsc.co1.qualtrics.com/jfe/form/SV_3qnL7XOwATnf0Al

APPENDIX F

PARTICIPANT ONLINE RAFFLE INTRODUCTION

By entering your information on the following page, you are willingly entering the raffle for one of five $20.00 Amazon gift cards.

You are eligible for this raffle because you completed the research questionnaire, "Patient Communication Preference Regarding Reclassified Genetic Test Results". Your information will not be distributed and will not be used to contact you unless you are the winner of the raffle.

If you would like to enter the raffle, please click the bottom button below. If not, please exit the survey.

APPENDIX G

PARTICIPANT ONLINE RAFFLE ENTRY

Please remember to submit this survey by hitting the blue arrow below

1. Please complete the form below:
    - First Name:
    - Last Name:
    - Preferred Title (Mr., Ms., Dr.):
    - Preferred Email: