Impact of a pre-counseling educational video on the duration of cancer genetic counseling sessions

by

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Background: Genetic counseling and testing is considered a necessary component of clinical care for patients who may be at risk for hereditary cancer syndromes. Appropriate genetic counseling and testing can impact medical management for these patients. There is a documented shortage of genetic counselors, leading to long wait times and inequity in access to these services. Many approaches are being studied to address these issues of access to genetic counseling and testing. This study aims to investigate whether having patients watch an educational video prior to their cancer genetic counseling appointment decreases the duration of the appointment. The goal of this research is to identify ways to streamline genetic counseling sessions so that genetic counselors have more clinical availability.

Methods: An eight-minute-long educational video was created by the cancer genetic counselors and the Medical Director of the Cancer Genetics Program at UPMC Magee-Women's Hospital. This video was sent to patients when they scheduled their appointment and they were encouraged to watch it prior to their appointment. Over the course of multiple years, the cancer genetic counselors documented whether or not their patients watched the educational video prior to the counseling session. They also documented the duration of each session, whether they had a student with them in the session, whether the session was virtual or in-person, and whether a pedigree was obtained during the session.

Results: Whether patients watched the educational video did not have a significant impact on the duration of the genetic counseling sessions. Sessions were significantly longer when there

was a student present or when a pedigree was taken during the session. Telemedicine sessions were significantly shorter than in-person counseling sessions.

Conclusion: The results of this research showed that the educational video did not impact appointment duration. However, there were limitations of this study. Namely, patients may have watched the educational video months before their appointment which may have impacted their recall of the information. This study did show that telemedicine counseling sessions were significantly shorter than in-person sessions, which suggests that virtual appointments may be helpful in increasing the efficiency of genetic counseling clinics.

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Preface

I would like to acknowledge and thank my thesis committee for their guidance and assistance throughout this project. This research would not have been possible without their expertise, editing, and input. I would also like to specifically thank my committee chair, Melissa Bourdius, for her unwavering support and encouragement this year.

In addition, I would like to thank all of the cancer genetic counselors at UPMC Magee-Women's Hospital for the time and effort they put into creating this dataset. I am so grateful that I was given the opportunity to work with this data that they have spent years collecting. Thank you especially to Darcy Thull for bringing this project to my attention. At a time when I was unsure of what topic to pursue for my thesis, the offer to look at this dataset was incredibly appreciated.

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1.0 Introduction

The field of human genetics has been expanding rapidly over the past few decades. As technologies have improved, genetic testing has become more accessible to the general population, which has led to an increased need for professionals to provide genetic counseling and testing, and to interpret and relay genetic test results. This service is generally provided by genetic counselors (GCs). For over a decade there has been a shortage of genetic counselors, leading to long wait times for appointments or limited access to genetics professionals due to geographical location (Raspa et al., 2021). This has been a topic of concern in the field for many years, which led, in 2015, to the creation of a formal workforce study to project the supply and demand of GCs through 2026. The data collected for this study demonstrated a shortage of clinical genetic counselors and predicted that the demand may not be met until 2030 (Hoskovec et al., 2018). The limited availability of genetic counseling services is complicated by issues of accessibility and healthcare inequities in urban vs rural areas (Raspa et al., 2021).

The primary focus of research in this area has been to address the issues of access to genetic counseling and testing services. One area that investigators have explored is the comparability of telemedicine and telephone appointments to the standard in-person genetic counseling appointment (Buchanan et al., 2015; Interrante et al., 2017). The virtual appointment options seek to address the issue of genetic counselors being physically inaccessible due to the lack of providers in some areas. However, these virtual appointments do not completely solve the access issue. The other dimension of the problem is simply the lack of available appointments, or long wait times, whether in-person or virtual (Raspa et al., 2021). One way to address this issue is to increase the efficiency of genetic counseling sessions. Several studies have concentrated on ways to provide

basic genetics information to patients prior to their genetic counseling appointment, so that the providers would be able to streamline the visits and allow for more appointments.

One study found that patient use of an educational computer program prior to the genetic counseling session led to significantly shorter counseling sessions among women at low risk for having a BRCA1/2 mutation (Green et al., 2005). In addition, they reported that in about half of the sessions that were preceded by use of the computer program, the counselor indicated that they were able to focus more on personal risk and decision-making instead of basic genetics information. In addition, a group in the Netherlands has published multiple papers on the use of a tailored educational website for patients before genetic counseling sessions. Patients in the intervention group, those given access to the educational website prior to counseling, more often shared their personal agenda with the counselor and directed the conversation during the GC appointment (Albada et al., 2012).

These papers demonstrate that there may be multiple benefits to providing succinct educational resources to patients prior to a GC appointment. In addition, finding ways to streamline GC appointments, no matter which service-delivery model is used, could help address the demand for genetic counselors' time. The current research is focused on the impact of an educational video, provided to patients before their counseling session, on the duration of cancer genetic counseling appointments.

The Cancer Genetics Program at UPMC Magee Women's Hospital created a genetics educational video which was provided to patients prior to their visit. The genetic counselors then collected data on whether patients watched the educational video before their appointment, and then kept track of the duration of each appointment. This study seeks to identify whether the use of a pre-counseling educational video impacts the duration of genetic counseling sessions,

controlling for other variables such as the participation of a GC student in the session, the service-delivery model used for the session, whether a family history was obtained before the session, and whether the appointment was an urgent referral. The results of this research will contribute to the understanding of the utility of an educational video in streamlining genetic counseling sessions.

1.1 Specific Aims

1. Assess whether having patients watch an educational video prior to their genetic counseling appointment impacts the duration of the genetic counseling session.
2. Investigate whether factors such as the participation of a genetic counseling student, the collection of the family history during the session, and whether the patient was an urgent referral affect the duration of the genetic counseling session.
3. Compare session duration for telemedicine versus in-person genetic counseling sessions.

2.0 Literature Review

Genetic testing for heritable cancers has become increasingly commonplace in the setting of clinical oncology. Approximately 10% of cancers are due to an underlying single-gene pathogenic variant. This pathogenic variant can be passed down through families, usually in an autosomal dominant manner, therefore impacting family members' cancer risks as well. In addition to impacting a person's risk for developing cancer, these genetic changes can also have implications for cancer treatment and risk management. Genetic counseling and testing are now considered integral components of clinical care for patients who are at increased risk for a hereditary cancer predisposition syndrome (Daly et al., 2021; Robson et al., 2015).

There have been multiple genes identified that confer increased risks for developing certain cancers. The two most well-known are the *BRCA1* and *BRCA2* genes. If a person has a pathogenic variant (PV) in one of these genes they are at increased risk for male or female breast cancer, ovarian cancer, pancreatic cancer, prostate cancer, and melanoma (*BRCA2* only) (Daly et al., 2021). The results of genetic testing can have serious implications for the medical management of a patient's cancer, from the type of surgery a patient chooses to the type of drugs, chemotherapeutic agents or other medications an oncologist considers for their treatment. Multiple studies have shown that identifying hereditary cancer syndromes, such as Hereditary Breast and Ovarian Cancer syndrome, through genetic testing can reduce risks of developing cancer and improve survival (de Jong et al., 2006; Domchek et al., 2010; Robson et al., 2015). In the case of pathogenic variants in the *BRCA1* and *BRCA2* genes, it has been shown that prophylactic surgeries for unaffected individuals, such as bilateral mastectomy and bilateral salpingo-oophorectomy, reduce the risk for developing breast and ovarian cancer, and decrease mortality from these cancers (Choi et al., 2021;

Domchek et al., 2010). For an individual who has cancer, the results of genetic testing might therefore influence their surgical management decisions. Given the potential for this information to significantly impact a person's medical care, it is crucial that people have access to these services.

While the number of genetic counselors in the US has continued to grow at a remarkable pace, doubling over the past 10 years, so too has the number of patients who would benefit from genetic counseling and testing services (*Professional Status Survey 2020: Executive Summary*, 2020). In the most recent edition of the National Comprehensive Cancer Network (NCCN) guidelines, updates were made to the criteria regarding when a personal cancer diagnosis or family history indicates referral for genetic counseling and testing services. The guidelines became more broad, now including any patient with triple negative breast cancer, regardless of their age at the time of diagnosis (Daly et al., 2021). As these criteria evolve and encompass more people, the number of patients who are referred for genetic counseling and testing increases dramatically. There are also groups of professionals that endorse that the next step in this field is to offer genetic counseling and testing to any woman with a breast cancer diagnosis (Manahan et al., 2019), or to progress to a population-screening model where all women are offered BRCA1/2 testing regardless of cancer history (Gabai-Kapara et al., 2014; Levy-Lahad et al., 2015). If the field does progress to one of these models, the demand for genetic counseling and testing services will outpace the growth of the genetic counseling workforce.

Moving to a population screening model would lead to a dramatic increase in the number of people eligible for genetic counseling and testing, but even without such a shift, there has already been a steady increase in people seeking these services. A study of people with ovarian cancer showed that genetic testing rates increased from 14.7% in 2008 to 46.4% in 2018 (Cham et

al., 2022). Increased awareness of genetic testing availability, in both patients and providers, may account for the growing number of patients being referred for genetic counseling and testing services. Though these numbers have steadily grown, there is still a subset of patients who qualify for these services but are not being appropriately referred. For example, all patients with ovarian cancer currently qualify for genetic testing, but all of these patients do not pursue genetic testing. Some of this may be due to personal choice, but a subset of eligible patients do not receive referrals to genetics. In the 2022 study by Cham at al. referral rates were similar among oncologists and gynecologic oncologists, but were significantly lower among other physicians. In a more recent study, looking at any patients meeting NCCN criteria for genetic testing for Hereditary Breast and Ovarian Cancer syndrome, about 30% of patients did not receive genetic counseling and/or testing. The main barrier to genetic counseling and testing identified for that subset of patients was a lack of referral from their oncologist (Swink et al., 2019).

These recent studies demonstrate that even with the current guidelines, there is a population of patients who are eligible for genetic counseling services who are not being provided the proper avenues to seek these services out. This is significant with regards to the issue of accessibility of genetics services for two reasons. First, if efforts are made to ensure that all patients who meet criteria for genetic counseling and testing are properly referred, this will lead to an increase in the ever-growing patient population. Additionally, these studies highlight one reason why having non-genetics professionals provide genetic testing may not always be the best option when considering ways to increase access to genetics services (Cham et al., 2022; Swink et al., 2019).

In some clinics, medical providers who do not have a background in genetics order genetic testing for their patients without the involvement of a genetic counselor. While this increases access to genetic testing, this is not a viable solution in many scenarios. Multiple studies have

shown that some healthcare providers, such as primary care doctors and OB/GYN residents, do not feel comfortable with their knowledge of genetic risk assessment and interpreting genetic test results (Haga et al., 2019; Hauser et al., 2018; Kathrens-Gallardo et al., 2021; Mikat-Stevens et al., 2015). These studies indicate that, at this time, many non-genetics professionals are not receiving the training they would need to carry-out appropriate genetic testing and delivery of results. In addition, at least one national insurance company requires that a patient has genetic counseling prior to genetic testing in order to for the testing to be covered by the insurance company (*Cigna's Genetic Testing and Counseling Program | Cigna*, 2016). For these reasons, having non-genetics professionals provide genetic counseling and testing services is not always an option when trying to increase access to these services.

2.1 The Workforce

In the U.S., as of April 2021, there were 5,629 certified genetic counselors. The genetic counseling profession has grown by over 100% in the past ten years, and there is expected to be similar growth over the next ten years (*Professional Status Survey 2020: Executive Summary*, 2020; *Professional Status Survey 2021: Executive Summary*, 2021). Though the field is growing rapidly, the demand for genetic counselors in some areas continues to outpace the number of available counselors. For over a decade there has been a shortage of genetic counselors, leading to long wait times for appointments and limited access to genetics professionals due to geographical location (Raspa et al., 2021).

This has been a topic of concern in the field for years, and led, in 2015, to the creation of a formal workforce study to project the supply and demand of genetic counselors through 2026. The

data collected in this study demonstrated a shortage of clinical genetic counselors and predicted that the demand may not be met until 2030 (Hoskovec et al., 2018). The limited availability of genetic counseling services is complicated by issues of accessibility and healthcare inequities in urban vs rural areas (Raspa et al., 2021). The geographic distribution of genetic counselors in the US is uneven, mirroring what has been seen in the healthcare field at large (Nguyen et al., 2021; *Professional Status Survey 2021: Demographics and Methodology*, 2021). Across the United States there are "healthcare deserts" which are defined as areas where people lack access to primary care providers, pharmacies, hospitals, and/or trauma centers. In a recent report, 80% of counties in the US fell into at least one of these categories (Nguyen et al., 2021). In the 2021 Professional Status Survey conducted by the National Society of Genetic Counselors two-thirds of U.S. respondents lived and practiced in an area classified as a Metropolitan Statistical Area (MSA). MSAs are defined by the U.S. Office of Management and Budget as a geographical region containing one or more counties that contain a city of 50,000 or more inhabitants (US Census Bureau, n.d.). This demonstrates the geographical inequity that persists when it comes to access to in-person genetic counseling services.

Another way to assess the accessibility of genetic counseling and testing services is to examine wait times for these appointments. One study looked at the typical wait times for a new-patient, nonemergent genetics appointment in 2015 and found that 20% of genetics professionals had a wait time of 1-3 months and 21% of genetic professionals had a wait time of greater than 3 months (Maiese et al., 2019). This study evaluated wait times for a variety of genetic professionals, including geneticists, metabolic dietitians, and nurses, in addition to genetic counselors.

Though there are concerns about wait times for non-urgent genetic counseling appointments, there have also been multiple studies showing that in many cancer clinics GCs are

able to accommodate urgent patients due to specially reserved appointment times (*Genetic Counselor Workforce*, n.d.; Knapke et al., 2016). In 2019, about 50% of clinical genetic counselors reported that they had open appointments available within one week (*Genetic Counselor Workforce*, n.d.). These statistics show that the issue of availability of genetic counseling is more nuanced than a shortage of counselors across the board. The wait time for a genetic counseling appointment varies widely. While many counselors reported that they could see a new patient within a week or two, about 22% of counselors reported that the wait time for the next available appointment at their clinic was 1 month or longer (*Profession Status Survey 2020: Service Delivery & Access*, 2020).

Multiple approaches are being used to address the issues of accessibility and availability of genetic counseling services. Methods that have been mentioned in the literature include telemedicine and telephone appointments, group counseling sessions, the use of genetic counseling assistants (GCAs), and provision of educational materials before genetic counseling sessions (Stoll et al., 2018). According to data from the National Society of Genetic Counselors Professional Status Survey, in 2020 36% of GCs used telephone appointments, 28% used web-based video appointments, and 7% used group counseling appointments (*Professional Status Survey 2020: Executive Summary*, 2020). In the following section we will summarize the existing literature about the benefits and drawbacks of each of these methods.

2.2 Telemedicine

One area that many investigators have explored is the comparability of telemedicine and telephone appointments to the standard in-person genetic counseling appointment (Buchanan et

al., 2015; Interrante et al., 2017). Studies have demonstrated the non-inferiority of telephone to in-person genetic counseling, and have shown that there are no clinically significant contraindicators for telephone counseling (Binion et al., 2021; Interrante et al., 2017; Kinney et al., 2016; Schwartz et al., 2014). These studies compared telephone counseling to in-person counseling on a number of measures including patient satisfaction, cost, knowledge after counseling, decisional conflict, anxiety, and cancer-specific distress. Telephone genetic counseling was noninferior to in-person counseling on all these measures. Similarly, studies have shown that video appointments are acceptable to both patients and counselors (Bradbury et al., 2016; Buchanan et al., 2015). One difference that was noted between these two forms of counseling was uptake of genetic testing. Two different studies both showed lower uptake of genetic testing in the telemedicine counseling arm versus the in-person counseling arm of the study (Buchanan et al., 2015; Schwartz et al., 2014). It has been hypothesized that this difference may be due to the fact that patients who receive genetic counseling in person often have the option of providing a DNA sample following their session, whereas patients who utilize telephone counseling often need to make a trip to a clinic in order to provide a DNA sample. The study by Buchanan et al., also found that patients with in-person appointments were significantly more likely to attend their appointment versus those with telemedicine appointments (attendance rates of 89% and 79%, respectively). Aside from these differences, telemedicine appointments have been shown to be comparable to in-person genetic counseling appointments.

These virtual appointment options seek to address the issue of genetic counselors being physically inaccessible due to the lack of providers in some areas. In addition, some clinics have found that virtual appointments also help to address the issue of appointment availability. In a proof-of-concept study, one clinic demonstrated that when doing only telephone appointments the

genetic counselors were able to see more patients per day, and therefore were able to decrease their wait times for new appointments (Eichmeyer, 2014). However, these virtual appointments do not completely solve the access issue. Though they do expand the reach of genetic counselors, not all patients have a reliable internet connection for video calls (*Demographics of Internet and Home Broadband Usage in the United States*, 2021; McNally, 2021). In addition, there has not been substantial research looking at whether virtual appointments impact wait times in clinics across the board. The use of group counseling sessions and pre-counseling educational materials both aim to increase the availability of genetic counseling appointments by decreasing the amount of time that a genetic counselor spends with each individual patient. This translates to the genetic counselor being able to see a larger volume of patients per week, which would help to address the issue of long wait times.

2.3 Group Counseling

A randomized trial in Canada compared group counseling to individual counseling for women who were referred to genetics due to a positive prenatal screening result (Cloutier et al., 2017). Group sessions could include 2-6 patients and patients' partners were welcome to join the session as well. The patient-focused outcomes that the study group evaluated included anxiety, perceived personal control, decisional conflict, knowledge (measured by 8 true/false questions), and satisfaction. Following both the group and individual counseling there was a significant decrease in patient-reported anxiety and decisional conflict. In addition, in both groups there was a significant increase in perceived personal control and knowledge following counseling. There were no statistically significant differences between the groups on satisfaction following

counseling, perceived personal control, decisional conflict, and knowledge. The one measure where there was a significant difference between groups was patient-reported anxiety. The decrease in anxiety following counseling was significantly greater for women who received individual counseling versus group counseling. This study also compared the amount of time the genetic counselors spent per individual patient and found that the group counseling did decrease the amount of time the counselor spent counseling per patient seen (Cloutier et al., 2017).

In comparing group counseling, individual counseling, and an interactive decision aid with optional counseling afterward, one research team found that each model had unique strengths. Participants in all groups showed an increase in knowledge and a decrease in decisional conflict post intervention (Hunter et al., 2005). However, those in the group counseling sessions showed a significantly greater increase in knowledge compared to those who received individual counseling. In contrast, those who had individual counseling showed significantly higher satisfaction scores than those in the group counseling or decision-aid arms. Participants who received the decision aid with optional counseling scored significantly lower on decisional conflict compared to those who had group counseling (Hunter et al., 2005). Other studies that have evaluated the feasibility of group counseling sessions, with or without additional "mini" individual sessions, show that both patients and genetic counselors rated that they were highly satisfied with the group counseling model (Hynes et al., 2020; Rothwell et al., 2012). This model seems to be a viable option for increasing the efficiency of genetic counseling clinics, however the feasibility of this model within the U.S. healthcare system needs to be studied further as most of the randomized trials have been conducted in Canada.

2.4 Educational Materials

Several studies have focused on ways to provide basic genetics information to patients prior to their GC appointment, so that the counselor can spend less time reviewing those concepts. One study, by Green et al. in 2005, evaluated the impact of a pre-counseling educational computer program on duration and content of GC sessions. This study found that use of the computer program led to significantly shorter counseling sessions among women at low risk for having a *BRCA1/2* mutation. Interestingly, the use of the computer program did not result in a significant difference in genetic counseling session times for women at high risk for having a *BRCA1/2* mutation. In addition to the impact on session duration, the genetic counselors reported that in about half of the sessions that were preceded by use of the computer program, they were able to focus more on personal risk and decision-making instead of basic genetics information (Green et al., 2005).

An additional study used a randomized noninferiority trial to compare outcomes when patients receive only written information about genetic testing (intervention group) versus a genetic counseling session (usual care) (Quinn et al., 2017). The study population included women who had recently been diagnosed with breast cancer and were being offered treatment-focused genetic testing. They found that the written materials were noninferior to the standard genetic counseling session with regards to decisional conflict about the genetic testing. They also found no significant differences between the two groups on measures of breast cancer-specific worry, anxiety, depression, and test-related distress. At the one-year follow-up timepoint they found no significant differences between the groups for decision regret about the genetic testing or uptake of risk-reducing bilateral mastectomy. The investigators concluded that this streamlined approach to treatment-focused testing may be a viable alternative to standard genetic counseling sessions.

A group in the Netherlands has published multiple papers on the use of a tailored educational website for patients before GC sessions (Albada et al., 2012). In 2012, they reported that patients in the intervention group (those given the educational website pre-counseling) more often shared their personal agenda with the counselor and directed the conversation during the GC appointment. An on-going four-armed noninferiority trial is evaluating how electronic genetic education only, electronic education with pre-test counseling, and electronic education with post-test counseling compare to the standard of pre- and post-test counseling (Swisher et al., 2020). At 3 months, each of the three experimental arms were noninferior to usual care on patient-reported levels of distress. In addition, there were no statistically significant differences on measures of anxiety, depression, and decisional regret across all of the arms at follow-up. This study found that completion of genetic testing was highest in the electronic education arm with no counseling, and lowest in the standard care arm.

These studies demonstrate that there may be multiple benefits to providing succinct educational resources to patients prior to a GC appointment. In addition to the possibility of streamlining the genetic counseling session, this model may allow for patients to more easily direct the session, leading to a more individually-tailored appointment. Many studies have taken this further, looking at the feasibility of replacing standard genetic counseling with educational materials. Though this may also be a reasonable option to increase access to genetics services, more research needs to be done on the broader psychosocial implications of this model, such as how it impacts patients' perceived personal control.

The current study aims to investigate whether a pre-counseling educational video may increase the efficiency of a cancer genetic counseling clinic located in a busy metropolitan area. Though there have been studies looking at the impact of various educational materials in the

context of genetic counseling sessions, to date there have not been any studies evaluating the use of an educational video in this clinical setting.

3.0 Manuscript

3.1 Background

Genetic counseling and testing are now considered integral components of clinical care for patients who are at risk for a form of hereditary cancer (Daly et al., 2021; Robson et al., 2015). There have been a number of genes identified that are associated with risks for developing certain cancers. If a person tests positive for a pathogenic variant in one of these genes there can be time-sensitive implications for their medical management (de Jong et al., 2006; Domchek et al., 2010; Robson et al., 2015). In the most recent edition of the National Comprehensive Cancer Network guidelines, changes were made that broadened the criteria regarding which patients qualify for genetic counseling and testing. The guidelines now state that any patient with triple negative breast cancer, regardless of their age at diagnosis, qualifies for genetic counseling and testing (Daly et al., 2021). The current demand for genetic counselors already outweighs the availability of counselors, and as the number of patients who are eligible for genetic counseling services increases this imbalance will only continue to grow.

For over a decade there has been a shortage of genetic counselors, leading to long wait times for appointments and limited access to genetics professionals due to geographical location (Raspa et al., 2021). This has been a topic of concern in the field for years, which led, in 2015, to the creation of a formal workforce study to project the supply and demand of GCs through 2026. The data collected in this study demonstrated a shortage of clinical genetic counselors and predicted that the demand may not be met until 2030 (Hoskovec et al., 2018). Multiple approaches, such as telemedicine appointments, group counseling sessions, and the provision of educational

materials before counseling sessions, are being studied to address these issues of access to genetic counseling services (Stoll et al., 2018).

Several studies have been conducted evaluating the impact of providing educational resources prior to counseling on the duration and content of genetic counseling sessions. One study, by Green et al. in 2005, evaluated the impact of a pre-counseling educational computer program on duration and content of GC sessions. This study found that use of the computer program led to significantly shorter counseling sessions among women at low risk for having a *BRCA1/2* mutation.

The current research aims to investigate how a pre-counseling educational video may increase the efficiency of a cancer genetic counseling clinic located in a busy metropolitan area. Though there have been studies looking at the impact of various educational materials in the context of genetic counseling sessions, to date there have not been any studies evaluating the use of an educational video in this clinical setting.

3.2 Methods

3.2.1 Ethical Considerations

This study was approved by the University of Pittsburgh Institutional Review Board (IRB). The data used for this study was previously collected by genetic counselors in the cancer genetics clinic; therefore this study was determined to fall under the exempt review category. Documentation is included in Appendix A.

3.2.2 Study Population

The study population included any patients that were seen by a cancer genetic counselor through the Cancer Genetics program at UPMC Magee Women's Hospital or the UPMC Hillman Cancer Center. These clinics provide genetic counseling services for patients who are above the age of 18 and either have a personal or family history of cancer.

3.2.3 Procedure

The genetic counselors and medical director at the cancer center at UPMC Magee Women's Hospital created an eight-minute-long educational video to send to patients prior to their genetic counseling appointments. This video focused on basic genetics concepts that would be relevant to any patient seeking genetic counseling related to cancer. The concepts covered in the video included a review of DNA, genes, chromosomes, and a basic description of why certain genetic mutations may increase a person's risk for cancer. The video was sent to patients through the MyUPMC app, if they had an active account, as soon as their appointment was scheduled. The URL link for the video was also written at the bottom of the appointment letter that is sent in the mail to patients who are scheduled for non-urgent appointments. For some patients, genetic counselor assistants would call about a week prior to their appointment to take a pedigree prior to the genetic counseling appointment. During these calls, the assistants would ask if the patient had received the link to the video. If the patient had not received the link the assistant would offer to email it directly to the patient.

The data used for this project was collected by cancer genetic counselors employed by the University of Pittsburgh Medical Center (UPMC) Health System. Data collection began in

February of 2018 and continued through November of 2021. For each patient, the genetic counselors would note the start and end time of the counseling session. The counselors also asked each patient if they had watched the educational video prior to the counseling session.

Information on whether a genetic counseling student or other observer was present in the counseling session and whether a family history was obtained prior to the appointment was recorded. Other information collected included whether the patient was urgently referred for a new cancer diagnosis, whether the session was conducted in-person or via video appointment, and whether the patient confirmed that they had received the video prior to the session. All of this information was documented by each genetic counselor in an Excel spreadsheet.

Patients were included in the dataset if we had complete information about the duration of their session and about whether they watched the video prior to their session. Additionally, if there were two or more family members receiving counseling together the session was only included in the dataset if the counselor noted the amount of time spent talking to each individual family member. Adhering to this inclusion criteria, we ended up with a dataset of 3,304 genetic counseling sessions.

3.2.4 Variables

Urgent. This variable identified whether the patient was scheduled for an urgent appointment due to a recent cancer diagnosis. Urgent appointments are generally scheduled within a week of receiving the referral. Patients qualify for urgent appointments if they have a recent diagnosis of cancer for which genetic testing could impact treatment/surgery decisions. Patients who do not qualify for urgent appointments are scheduled on the normal schedule, which generally schedules out months in advance.

Telemedicine. Whether the session was conducted virtually via video call or in-person at the clinic.

Pedigree. Marked as "yes" if a family history needed to be taken during the session or "no" if the genetic counselor already had the family history before the session.

Student. Whether a student was present, either observing or participating, during the session or not.

Video. Denotes whether the patient watched the educational video before the genetic counseling session.

3.2.5 Data Analysis

We first performed *t*-tests to identify variables that significantly impacted the duration of the genetic counseling sessions. We then put all the variables of interest into a multiple linear regression model, which predicts the value of a dependent variable based on two or more independent variables, to identify independent predictors of the duration of a session. We also ran a logistic regression looking at patients' age and whether they watched the educational video.

3.3 Results

We had data for a total of 3,304 appointments in this dataset. As displayed in Table 1, the mean duration of the genetic counseling sessions was 47 minutes. About 67% were regularly scheduled appointments and 32% were urgently scheduled appointments due to a new cancer diagnosis. Approximately 24% of sessions had a student present while about 76% of sessions did

not. In addition, in about 66% of sessions a pedigree had been obtained before the appointment. See Table 2 for the exact breakdowns of all of the binary variables.

Table 1 Descriptive statistics for age and session duration

Variable	Mean	Std. Dev.	Min	Max
Duration (minutes)	47	14.16	10	133
Age	51.91	14.63	18	95

Table 2 Frequency Table of Binary Variables

	Urgent		Pedigree		Student		Telemedicine		Video	
	N	Y	N	Y	N	Y	N	Y	N	Y
Frequency	2,235	1,069	2,171	1,133	2,500	804	2,358	946	2,495	809
Percent	67.65	32.35	65.71	34.29	75.67	24.33	71.37	28.63	75.51	24.49

We began by performing *t*-tests to identify univariate predictors of session duration (See Table 3). We found that sessions that were urgent referrals took longer than sessions that were on the normal schedule ($p = 4.848 \times 10^{-5}$). We also found that taking a pedigree in the session ($p = 5.145 \times 10^{-43}$) and having a student present during the session ($p = 4.788 \times 10^{-8}$) both significantly increased the duration of the counseling session. Sessions that were conducted via telemedicine were significantly shorter than sessions conducted in-person ($p = 1.591 \times 10^{-63}$). When looking at session times for patients who watched the educational video beforehand versus those that did not, no statistically significant difference was found between the two groups ($p = .89$).

Table 3 Univariate predictors of session duration

	Duration of counseling session in minutes, Mean (SD)				
	Urgent	Pedigree	Student	Telemedicine	Video
Yes	48.77 (12.75)	51.95 (14.05)	49.69 (14.86)	40.91 (12.82)	47.38 (13.66)
No	46.63 (14.74)	44.91 (13.62)	46.55 (13.85)	49.89 (13.86)	47.30 (14.32)
p-value	4.848×10^{-5}	5.145×10^{-43}	4.788×10^{-8}	1.591×10^{-63}	0.8944

After putting these variables in a multiple linear regression model, we saw that the nature of the session (urgent vs. standard) was no longer a significant predictor of session duration. All other variables that showed significance in the *t*-tests remained significant in the linear regression model with the same directions of effect (see Table 4). This model showed that on average, with all other variables controlled for, telemedicine sessions were 8.17 minutes shorter than in-person sessions ($p = 8.720 \times 10^{-52}$). When a pedigree was taken during the session, the appointment was on average 6.81 minutes longer than sessions where a pedigree was not taken ($p = 8.225 \times 10^{-45}$). Sessions that had a student present were on average 2.7 minutes longer than sessions without a student ($p = 3.985 \times 10^{-7}$). In this model we also saw that patient age was a significant predictor of session duration, such that with each increasing decade of the patient's age, the session was on average 1.6 minutes longer ($p = 2.745 \times 10^{-26}$). The R-squared value for this linear regression was 0.19, indicating that 19% of the variation in duration of genetic counseling sessions is accounted for by this group of variables. By running an *F*-test, we were able to determine that the genetic counselor variable does have a significant impact on the duration of the session, $F(8, 3285) = 17.50$, $p < 0.001$.

We also stratified this linear regression by whether the patient had an urgent appointment. This was done because of differences in the scheduling process for urgent versus non-urgent

patients. Urgent patients are generally scheduled within 1-2 weeks of requesting a genetic counseling appointment, so we hypothesized that many of these patients may not have had an opportunity to view the video. However, we found that 273 urgent patients were able to watch the video prior to the appointment. As illustrated in Tables 5 and 6, when this analysis was stratified by the Urgent variable, there was no difference in variables that achieved statistical significance compared to the original regression model. There are slight differences in the coefficients for the various variables, however the directions of all of the effects remained the same in each of these regression models.

Finally, we ran a logistic regression to investigate the relationship between patient age, whether they had an urgent appointment, and whether the patient watched the educational video (see Table 7). This model did not show any evidence that age impacted whether the patient watched the video before the appointment (OR = 0.9967, 95% CI [0.99127, 1.00217]). The model also did not show any evidence that whether the patient had an urgent or regular appointment impacted whether the patient watched the video before the appointment (OR = 1.0975, 95% CI [0.92646, 1.30017]).

Table 4 Linear Regression

Variable	Coefficient	Std. error	*p*-value	95% Confidence Interval	
Urgent	-0.7528153	0.5024708	0.1342	-1.738003	0.2323723
Telemedicine	-8.167295	0.5299374	8.720×10^{-52}	-9.206336	-7.128254
Student	2.698189	0.5316485	3.985×10^{-7}	1.655793	3.740585
Pedigree	6.807553	0.4773754	8.225×10^{-45}	5.871569	7.743536
Video	-0.2157543	0.5301401	0.6841	-1.255193	0.8236841
Genetic Counselor					
1	-0.6215786	1.508724	0.6804	-3.579714	2.336557
2	-2.790242	1.418833	0.0493	-5.572128	-0.0083558
3	1.751076	2.264228	0.4394	-2.688365	6.190518
4	3.968056	1.821966	0.0295	0.3957513	7.54036
5	1.138631	1.425007	0.4243	-1.655361	3.932624
6	-3.406271	1.468624	0.0204	-6.285782	-0.5267601
7	-5.228739	1.410819	0.0002	-7.994912	-2.462566
8	2.441334	2.004206	0.2233	-1.488286	6.370954
Age	0.1638313	0.0153121	2.745×10^{-26}	0.1338092	0.1938535
_cons	40.34543	1.568149	0.00	37.27079	43.42008

Table 5 Linear Regression of Regular Appointments

Variable		Coefficient	Std. Error	*p*-value	95% Confidence Interval	
Telemedicine		-8.317549	0.603112	1.446×10^{-41}	-9.500273	-7.134826
Student		2.650002	0.6312511	2.775×10^{-5}	1.412097	3.887907
Pedigree		7.689709	0.6057064	1.006×10^{-35}	6.501897	8.87752
Video		-0.0812479	0.6648618	0.9027	-1.385065	1.222569
Genetic Counselor						
	1	0.2245933	1.919995	0.9069	-3.540584	3.98977
	2	-2.994336	1.805837	0.0974	-6.535644	0.5469724
	3	0.006665	2.783191	0.9981	-5.451268	5.464598
	4	2.38156	2.153429	0.2689	-1.841388	6.604509
	5	0.5681847	1.807897	0.7533	-2.977165	4.113534
	6	-4.518696	1.858025	0.0151	-8.162347	-0.8750455
	7	-7.218012	1.791402	0.0001	-10.73101	-3.70501
	8	1.278968	2.477451	0.6057	-3.579399	6.137335
Age		0.1706335	0.0176972	1.426×10^{-21}	0.1359287	0.2053383
_cons		40.59922	1.914004	0.0000	36.8458	44.35265

Table 6 Linear Regression of Urgent Appointments

Variable		Coefficient	Std. Error	*p*-value	95% Confidence Interval	
Telemedicine		-5.649988	1.168615	1.567×10^{-6}	-7.943061	-3.356915
Student		2.667064	0.9895804	0.0071	0.7252947	4.608834
Pedigree		5.243111	0.7678731	1.432×10^{-11}	3.736379	6.749843
Video		-0.9994118	0.8692078	0.2505	-2.704984	0.706161
Genetic Counselor						
	1	-2.728592	2.380232	0.2519	-7.399119	1.941936
	2	-3.004901	2.245036	0.181	-7.410145	1.400344
	3	5.875201	3.850303	0.1273	-1.679921	13.43032
	4	12.89252	4.255511	0.0025	4.542289	21.24274
	5	1.443557	2.269666	0.5249	-3.010016	5.89713
	6	-1.989643	2.354354	0.3983	-6.609392	2.630105
	7	-2.012667	2.237498	0.3686	-6.40312	2.377786
	8	4.540147	3.367114	0.1778	-2.066854	11.14715
Age		0.1433145	0.0309661	4.112×10^{-6}	0.0825525	0.2040766

_cons	40.37505	2.80025	0.0000	34.88036	45.86974	

Table 7 Logistic Regression of Age and Urgent Appointment Video

Variable	Odds Ratio	Std. Error	z	*p*-value	95% Confidence Interval	
Age	0.9967079	0.0027807	-1.18	0.2372	0.9912727	1.002173
Urgent	1.097525	0.0948802	1.08	0.2817	0.9264649	1.30017
_cons	0.3734569	0.0556961	-6.6	0.0000	0.2788016	0.5002484

3.4 Discussion

In this research we sought to identify whether having patients watch an educational video before their genetic counseling session decreased the duration of the session. We also evaluated other variables that we hypothesized could impact the duration of a genetic counseling session, such as whether the session was virtual or in-person. We found that patient use of the educational video did not significantly impact the duration of the genetic counseling sessions. However, telemedicine sessions were significantly shorter, on average, than standard in-person sessions. We also found that whether a pedigree was taken during the session, whether a student was present in the session, and the age of the patient all had a statistically significant effect on session duration.

With regards to the primary hypothesis of this study, our data suggests that having an optional educational resource given to patients before a genetic counseling appointment may not reduce the duration of the appointment. Though there is a paucity of literature on this topic, a study by Green at al. found that the use of an educational website prior to a genetic counseling session only impacted the duration of the session for a subset of patients. They found that use of the

educational website was associated with shorter session times for patients at low risk for having a *BRCA1/2* mutation but that it did not significantly impact the duration of the session for patients at high risk for a *BRCA1/2* mutation (Green et al., 2005). However, in that study, genetic counselors noted that use of the educational materials seemed to impact the content of the session. Genetic counselors reported that in about half of the sessions that were preceded by use of the computer program, they were able to focus more on personal risk and decision-making instead of basic genetics information (Green et al., 2005). In the current research we did not do qualitative analyses looking at how the use of the educational video may have impacted the content of the session. It is possible that although we did not see a difference in duration of sessions between those who watched the video and those who did not, there may have been a difference in how the sessions were conducted. Future research in this area could inform whether the use of educational materials prior to genetic counseling is beneficial for the patient and genetic counselor, even if it does not impact session duration.

In addition, our analyses were not broken down by which patients were at high or low risk for carrying a pathogenic variant. Given that the study by Green et al. found that utilization of the educational materials impacted these groups differently, it would be interesting to explore if that finding holds true in other populations. It is possible that there are patient-specific characteristics that impact how useful the educational video is for the patient, and how much it impacts session duration. This information could be useful in deciding how to best implement the use of educational materials in various clinical settings.

Another area that should be considered for future research is patient perspectives on the use of educational materials prior to genetic counseling sessions. In evaluating the benefits of these educational materials, it is important to understand if patients find them helpful. Some similar

studies that have evaluated the use of educational materials have asked patients to give feedback about the clarity of the resources (Meiser et al., 2012; Quinn et al., 2017). However, there is not much research on whether patients desire these resources or feel that they help them prepare for appointments. Understanding patients' views on the use of these materials prior to clinic visits would be helpful in assessing the utility of these resources. Along these lines, it would be interesting to explore how patient characteristics like anxiety and information-seeking tendencies may influence perceived usefulness of these materials, along with likelihood to use educational materials prior to a session.

While the educational video did not affect the duration of the genetic counseling sessions, many of the other variables that we looked at did have an impact. As we expected, having a student present in the session and having to take a pedigree during the session both increased the duration of the sessions. We also saw that telemedicine appointments were significantly shorter than in-person sessions. This data suggests that in addition to improving access by removing geographical barriers, virtual genetic counseling appointments may be less time-consuming than standard in-person sessions. Though there is a large amount of research on the noninferiority of telemedicine genetic counseling appointments compared to standard in-person appointments, there has not been much focus on the duration of these different types of sessions (Bradbury et al., 2016; Buchanan et al., 2015; Interrante et al., 2017; Schwartz et al., 2014). The findings from our study suggest that telemedicine appointments should be considered and studied as a means to increase efficiency in genetic counseling clinics.

In this research we did not evaluate factors that could explain why the telemedicine appointments were shorter, on average, than in-person sessions. One possible explanation could be that counselors do not go into as much detail during telemedicine sessions. Though this may be

the case, previous studies have shown that telemedicine genetic counseling sessions are noninferior to in-person sessions when it comes to post-counseling patient knowledge and patient satisfaction (Interrante et al., 2017; Schwartz et al., 2014). Given that patient knowledge did not significantly differ in these studies, it seems that at least to a certain extent, the same amount of information is being conveyed. Another possible explanation is that counselors may spend less time addressing psychosocial concerns during telemedicine sessions. Multiple studies have shown that counselors find it more difficult to read non-verbal cues during virtual appointments, which can limit their ability to perform psychosocial counseling (Mills et al., 2021; Zierhut et al., 2018). Less time spent exploring psychosocial concerns could be a contributing factor to why telemedicine sessions were shorter than in-person counseling appointments.

It is also possible that telemedicine visits were shorter than in-person visits because in-person sessions include additional components that may not occur during face-to-face time with telemedicine patients. For example, if a patient is getting their blood drawn immediately following the counseling session, the counselor may be placing orders for the blood draw and obtaining written consent during the session. In the UPMC Cancer Genetic Program, there is also a cancer family registry that patients can elect to join. If the patient is interested, the counselor would also review the registry consent form during an in-person session. For these reasons, it's possible that telemedicine sessions were shorter solely because some of the steps involved in coordinating genetic testing, which are done during the session for in-person visits, are done after the session is over for telemedicine visits.

In our data analysis we also found that for every decade older a patient was, the session was, on average, 1.6 minutes longer. This is not something that has been focused on previously in the literature. Though we do not know why session duration increased as patient age increased,

one hypothesis is that older patients may have more detailed family history information to share with the counselor. It's also possible that with older patients, more time may be spent talking about implications of genetic testing for family members and children.

In looking at the relationship between patient age and use of the online educational video, we found that patient age did not have an impact on whether a patient watched the video before their appointment. This suggests that online educational materials are equally accessible to patients of various ages. This finding is encouraging, as many aspects of healthcare have shifted to virtual platforms in recent years due to advancements in technology and the Covid-19 pandemic. As more research is conducted on various types of patient-facing educational resources, it will be important to continue to evaluate whether the materials are accessible to patients of various ages given the wide range of patients seen in genetic counseling clinics.

3.4.1 Limitations

One limitation of this study was the fact that the educational resource was optional and distributed to all patients. This may have led to a selection bias, where personal characteristics among patients who watched the video may also be characteristics that impact the duration of the session. For example, if a person is an "information-seeker" they may be more likely to watch the video before the appointment but may also be more likely to have questions during the appointment that would lengthen the overall duration. One way to address this possible confounding factor would be to randomize patients to receive the educational video versus not. This would not completely remove this possible bias unless all patients in the video group watched the video, but it may help reduce the impact of this bias.

Similarly, there may have been a form of selection bias with regards to patients who chose to do telemedicine appointments versus in-person visits. It's possible that patients who chose telemedicine visits did so because they had less time to dedicate to the genetic counseling appointment. Telemedicine visits naturally save time for the patient because they do not need to commute to the healthcare facility. If the patients who chose telemedicine visits were doing so because they were busy and were hoping to save time, it's possible that this may be a confounding factor in our assessment of the duration of telemedicine versus in-person appointments.

Another limitation of this research was the fact that some appointments in the dataset were sessions for updated testing, meaning the person had likely had a full genetic counseling session at a previous time. These sessions can be shorter than standard genetic counseling sessions, but this difference in referral reason was not noted in the available dataset. If these sessions were not randomly distributed between telemedicine and in-person visits this may have been a confounding factor for our comparison of the duration of these two modes of counseling sessions.

In addition, given the length of time between sending out the educational video and the patient's counseling session, it is possible that some patients watched the video months before their appointment while others may have watched it within a week prior to the appointment. In the study by Green et al. when the use of the educational materials decreased session duration for some patients, the patients were accessing the educational website immediately prior to their genetic counseling session. In the current research, the amount of time elapsed between patients watching the video and their actual appointment may be a confounding factor that was not accounted for in our analyses. It could be that the video would have more impact on the duration and content of counseling sessions if all patients had watched the video within a week of their scheduled

appointment. In future studies, it may be helpful to standardize the time between viewing the video and the counseling session to remove this potential confounding factor.

Finally, in our dataset we did not have information about why the patient was referred for genetic counseling or what was discussed during the counseling session. This information would have allowed for a more nuanced analysis of the effects of the educational video. It's possible that having patients watch the educational video prior to their appointment may have impacted the content of the genetic counseling session. Future work should aim to include qualitative analyses of the content of the sessions, as the educational video may have allowed the counselors to focus more on personalized risk assessments and management discussions. It would also be important to identify whether there is a subset of patients for whom the educational video is most beneficial. Including the patients' reason for referral in the analysis may be helpful, as previous research has shown that there can be a differential impact of educational materials on session duration for patients who are at high vs low risk of having a *BRCA1/2* pathogenic variant (Green et al., 2005).

3.5 Conclusion

This study aimed to determine whether having patients watch an educational video prior to their cancer genetic counseling appointment impacted the duration of the appointment. We were able to evaluate data from over 3,000 cancer genetic counseling appointments conducted by genetic counselors within the UPMC Health System. Our analysis showed that the educational video did not impact the duration of the counseling session. Analyses of our other variables showed that having a student present in the session and needing to take a pedigree in the session both increased the duration of the session. Conversely, sessions conducted via telemedicine were

significantly shorter than standard in-person sessions. This suggests an additional benefit of telemedicine that is not often cited, that these appointments may increase the efficiency of a clinic given their, on average, shorter duration.

The analysis of the impact of the educational video was limited by the fact that patients may have watched the video months before their appointment, and that individual patient characteristics may have influenced both whether someone chose to watch the video and the duration of their appointment. It is also possible that while the video did not affect the duration of the sessions, it may have impacted the content of the counseling sessions. Future research in this area would clarify whether patients and genetic counselors find that the use of educational materials before an appointment is beneficial, regardless of the impact on session duration.

4.0 Significance to Genetic Counseling and Public Health

The aim of this research was to identify whether having patients watch an educational video prior to genetic counseling appointments impacted the duration of the counseling session. This is directly relevant to the on-going efforts in the field of genetic counseling to increase availability of genetic counseling and testing. This data provides information about a service delivery model that was hypothesized to streamline genetic counseling sessions, thereby increasing the efficiency of sessions, and allowing counselors to see more patients. In our study we did not see an impact of the video on session duration, indicating that the use of educational materials may not always reduce the amount of time that a genetic counselor spends with a patient. Though there may be other benefits to providing educational materials prior to genetic counseling appointments, this approach may not be the best way to increase efficiency in genetic counseling clinics.

This study did identify that on average, telemedicine sessions are shorter than in-person counseling sessions. This supports the body of research that has demonstrated multiple ways in which telemedicine genetic counseling improves access to these services (Buchanan et al., 2015; Interrante et al., 2017; Jacobs et al., 2016). Continuing to increase the accessibility of genetic counseling and testing services is important not only within the field of genetic counseling, but also in the realm of general public health.

Genetic counseling is a healthcare service that should be, but is not, accessible to all patients who qualify for genetic testing. Genetic counseling and testing can impact medical management decisions for individuals who discover that they have a hereditary cancer syndrome (Daly et al., 2021; Robson et al., 2015). Having these services available, specifically in the cancer setting, has been shown to decrease cancer diagnoses and mortality from cancer (Choi et al., 2021;

de Jong et al., 2006; Domchek et al., 2010). These statistics demonstrate the large impact that a lack of these services can have on incidence and survival rates of cancer. Disparities in access to genetic counseling and testing can therefore lead to disparities in health outcomes. Identifying ways to increase access to genetic services ties directly into one of the ten essential public health services, "enable equitable access." Ensuring equitable access to genetic counseling and testing is necessary to ensure equitable health outcomes.

In a broader context, genetic counseling is a service that involves communicating health information and health risks to patients. Genetic counselors are specifically trained to communicate this type of information effectively, regardless of the clinical setting in which they work. This aligns with another area of the essential public health services, which is to "communicate effectively to inform and educate people about health, factors that influence health, and how to improve it." Increasing the availability of genetic counseling services would enable more patients to have access to patient-friendly information that could help them make individualized decisions about their healthcare.

Finally, this project contributes to the field of public health by analyzing the efficacy of an alternative service-delivery model. Providing essential public health services involves improving systems through research and maintaining a strong infrastructure for public health. This project looked specifically at factors that may impact the use of genetic counselors' time, which contributes to the improvement of the overall infrastructure in place for providing genetic counseling. Finding alternate service-delivery models that increase efficiency in clinics and maximize the utility of genetic counselors' time is a public health driven effort by nature. Although we did not find that the educational video impacted the duration of the genetic counseling sessions, we did identify that telemedicine session were significantly shorter than in-person sessions. These

findings contribute to the fields of genetic counseling and public health by illustrating factors that should be considered when attempting to streamline genetic counseling sessions with the purpose of increasing the availability of these services.

Appendix A IRB Approval

University of Pittsburgh | Institutional Review Board
Office of Research Protections

EXEMPT DETERMINATION

Date:	February 17, 2022
IRB:	STUDY21100062
PI:	Savannah Binion
Title:	Impact of a pre-counseling educational video on the duration of cancer genetic counseling sessions

The Institutional Review Board reviewed and determined the above referenced study meets the regulatory requirements for exempt research under 45 CFR 46.104.

Determination Documentation

Determination Date:	2/17/2022
Exempt Category:	(4) Secondary research on data or specimens (no consent required)

Approved Documents:	• Exempt Application Form, Category: IRB Protocol; • Unofficial Honest Broker Assurance Form, Category: Honest Broker Signed Agreement;

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, Ali Arak.

Please take a moment to complete our Satisfaction Survey as we appreciate your feedback.

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