EVALUATING A WEBINAR SERIES DESIGNED TO EDUCATE GENETIC COUNSELING STUDENTS ABOUT THE APPLICATIONS OF LABORATORY GENETIC COUNSELING

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ABSTRACT

Due to the growth of genetic technology, genetic counseling training programs are challenged with building a foundation of knowledge in a constantly evolving field. As a result, there is a struggle to incorporate more educational content into training programs to ensure students' success as practitioners without increasing the overall length of training programs.

GeneDx, a commercial laboratory, has been involved in the training of students interested in learning more about the laboratory applications of genetic counseling. In the past, they had welcomed students onsite to gain this experience, but with the increased demand for clinical placements with ACGC's requirements for all genetic counseling students to have laboratory experience, the requests for placements have outweighed GeneDx's ability to accommodate all interested students. To meet the needs of those unable to rotate on site, GeneDx created an eight-week webinar series highlighting the unique role of a genetic counselor in the laboratory setting. This series included seven lectures and one panel discussion.

The purpose of this project was to evaluate the effectiveness of the GeneDx webinar series in educating genetic counseling students about the laboratory applications of genetic counseling as well as the satisfaction of both the students and program directors with the series.

Pre and post-lecture quizzes were used to assess students' knowledge of the material contained in the seven lectures. Paired t-tests identified statistically significant increases in knowledge for four of the seven lectures ($\alpha = 0.05$). Post-lecture and post-series satisfaction

surveys were also administered to gauge participant satisfaction. These results indicate that genetic counseling students and program directors felt that this was a positive learning experience.

This project is of public health significance due to the increasing demand for and availability of genetic testing, which is often facilitated by a genetic counselor. In order to meet the needs of a growing patient population with an increasing array of genetic testing options, it is important that genetic counseling students have specialized training in the laboratory applications of the profession prior to entering into the field.

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PREFACE

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1.0 INTRODUCTION

In the past, it was less challenging for genetic counselors to keep pace with the field of genetics, as available testing technologies were limited. Since the implementation of the Human Genome Project, however, there has been a rapid growth in genetic technology, which has created new professional opportunities for genetic counselors. In fact, the United States Department of Labor Bureau of Labor Statistics projects a 29% growth rate for genetic counseling jobs between 2014 and 2024¹, as compared to the 7% average increase across all other professions.² Along with those opportunities come new challenges. For example, genetic counseling training programs face the challenge of trying to build a solid foundation of knowledge in a field that seems to always be evolving.

In the United States, genetic counseling programs are usually two academic years in length, and in these two years students must complete coursework, clinical rotations in a variety of settings, and a scholarly project.³ To stay current, program directors are constantly challenged with increasing the amount of information that their students receive without increasing the overall length of their programs.

One content area that is required for genetic counseling programs by the Accreditation Council for Genetic Counseling (ACGC) is laboratory experience.³ Programs must provide their students with instruction in, and observation of, genetic laboratory activities and ensure that students have the opportunity to interface with laboratory professionals.³ This ACGC requirement is important for two reasons.

First, there are an increasing numbers of laboratory services and expanded genetic testing menus⁴, so it is important that clinical genetic counselors, who may be involved in the ordering of genetic tests for the patients that they see in clinic, are aware of their options and can make appropriate decisions on behalf of their patients. Second, a growing number of genetic counselors are choosing to work in the laboratory setting. This role differs from that of a clinical genetic tests and the interpretations of genetic test results.⁴ 10.2% of genetic counselors who order seponded to the National Society of Genetic Counselors (NSGC) 2016 Professional Status Survey report laboratory work or genetic testing as a primary area of work.⁵ For the subset genetic counselors who do not counsel patients, 31% claim that genetic testing is their primary specialty.⁵

In the past, GeneDx, a commercial genetic testing laboratory based in Gaithersburg, Maryland, had welcomed genetic counseling students on-site for a few weeks each year in order to introduce them to various laboratory technologies and the role that a counselor can play in the laboratory setting. While GeneDx continues to host many on-site students each year, more recently the demand for such placements has outweighed GeneDx's ability to accommodate all interested students. In order to provide more students with laboratory experience, GeneDx created an eight-part webinar series entitled "Behind the Scenes: Lessons from Laboratory Genetic Counselors" in which genetic counselors present lectures and lead discussions on a variety of laboratory-focused genetics topics.

By offering this webinar series remotely, more students are able to participate in this experience than would otherwise be reasonable due to time and geographical constraints. In

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addition to this benefit, there is also evidence to support that online learning is as effective in educating students as traditional in-person learning.^{6,7} Research on this subject has been done for some applications of distance learning in other medical professions, but to our knowledge, not specifically for genetic counseling students.

The goal of this project was two-fold. Because there is increasing emphasis on evidencebased education programs⁸, the first goal was to determine the effectiveness of this pedagogical approach in educating genetic counseling students about the laboratory applications of genetic counseling. The second goal was to assess genetic counseling students' and program directors' satisfaction with the course to evaluate whether they found the webinar series to be worth the investment of their time. If the GeneDx webinar series was found to be an effective approach in educating students and students as well as program directors were satisfied with the series, then perhaps it can be a resource for incorporating such laboratory-based content in training programs in an efficient way.

In order to evaluate the effectiveness of this webinar series as an educational tool, the webinar project team created pre and post-lecture quiz questions to measure students' knowledge on the different lecture topics. A statistically significant increase in post-lecture scores as compared to pre-lecture scores would suggest that the webinar series was effective in improving genetic counseling students' knowledge.

To determine participant satisfaction with the series, the GeneDx webinar team distributed post-lecture and post-series satisfaction surveys. These surveys are a mixture of Likert-scale questions and open-ended questions, which were designed to assess participant satisfaction with various aspects of the lecture such as speaker quality and content and also to assess participant overall satisfaction with the series. Additionally, at the conclusion of the

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series, genetic counseling program directors were also sent a short satisfaction survey to ascertain their thoughts on the value of this experience for their students.

This project is of particular public health significance due to the increasing demand for and availability of genetic testing. In a 2016 poll conducted by STAT and Harvard T.H. Chan School of Public Health, it was found that 6% of randomly sampled Americans have already undergone genetic testing for a number of reasons, suggesting that genetic testing is becoming more commonplace.⁹ In this same survey, a subset of respondents were asked about their desire to have predictive genetic tests for diseases like Alzheimer's and cancer, and more than 50% of people said that they would want to have such testing if it were available to them.⁹

Another survey conducted in 2016 among Amazon Mechanical Turks indicated that a majority of individuals (64.92%) would take a genetic test immediately to learn more about their hereditary predisposition to cancer, and another 26.84% would consider doing so sometime in the future.¹⁰

Genetic testing is often facilitated by a genetic counselor who can be involved from the clinical side in ordering a test or discussing results with a patient, the laboratory side in liaising with clinical staff or writing reports, or both. There is an increasing importance of educating genetic counseling students about the laboratory applications of the profession to ensure that they are prepared to enter the workforce with functional knowledge of genetic testing options, regardless of the specialty that they choose.

1.1 STUDY QUESTION

Question: Is the GeneDx webinar series an effective pedagogical approach for educating genetic counseling students about the laboratory applications of genetic counseling?

1.2 SPECIFIC AIMS

Aim 1: To analyze responses to pre and post-lecture questions to determine if there is a statistically significant increase in knowledge as a result of the GeneDx webinar series.

Aim 2: To analyze post-lecture and post-series surveys to determine if genetic counseling students and program directors were satisfied with the GeneDx webinar series.

2.0 LITERATURE REVIEW

2.1 GENETIC COUNSELING

2.1.1 Background

The definition of genetic counseling, according to the National Society for Genetic Counselors (NSGC), is: "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following: (1) Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence, (2), Education about inheritance, testing, management, prevention, resources and research, and (3) Counseling to promote informed choices and adaptation to the risk or condition.¹¹"

Genetic counselors work in a variety of clinical and non-clinical settings such as private hospitals, university-based medical centers, private practice, and industry, and opportunities continue to emerge.¹² In general, the role of a clinical genetic counselor is to provide risk assessment, education, and support for patients and families who might be at risk of having a genetic condition.¹³ Like other health professionals, genetic counselors can provide general care or can specialize in specific areas such as pediatrics, cancer, neurology, and more.¹⁴

Due to the increasing number of available genetic testing services, a growing number of genetic counselors are specializing in laboratory work to some degree⁴. In fact, 10.2% of genetic counselors who responded to the National Society of Genetic Counselors (NSGC) 2016 Professional Status Survey now report laboratory work or genetic testing as a primary area of work.⁵ For the subset genetic counselors who do not counsel patients, 31% claim that genetic testing is their primary specialty.⁵

Laboratory-based genetic counseling is a relatively new specialty. A 2016 study of 121 laboratory-based genetic counselors (LBGC's) by Waltman et al. found that the mean length of employment in a laboratory was 4.3 years and that almost one fifth of those individuals were the first LBGC in their company.⁴ Because this specialty is so new, a number of studies have been done to try to define the scope of practice of a LBGC, which will aid in the development, expansion, and exposure of LBGC positions.^{4,15–18}

Building on the work of Christian et al. (2012)¹⁵, Waltman et al. (2016) set out to further define the role of the laboratory genetic counselor and assess the activities that they perform on a day-to-day basis.⁴ Of all reported job activities, the one that LBGC's reported as spending most of their time performing was customer liaising/case coordination (30.2% of their time). Some responsibilities in this category included addressing questions about testing strategies, turn-around-times, and specimen requirements, and managing high priority cases.⁴ The second highest percentage of LBGCs' time (26.1%) was reportedly spent on results interpretation and reporting.⁴ Within this category, responsibilities included calling out genetic testing results, obtaining clinical/family history information to use during result interpretation, and reviewing literature to support result interpretation.⁴ These results were corroborated by the findings of Christian et al. (2012).^{4,15}

Other documented responsibilities of LBGC's included sales and marketing, counseling patients, research, management, test development and performance, website and database support, education and supervision of students, and insurance and billing.⁴ Though these tasks accounted for less than 10% of a LBGC's time each⁴, they demonstrate the breadth and depth of the role of the LBGC.

Despite the fact that the role of a LBGC is distinct from that of a clinical genetic counselor, the same basic skill set is utilized by genetic counselors in both settings.¹⁶ For example, both clinical genetic counselors and LBGC's use contracting as a means of setting expectations with their clients.^{16,17} In the clinic, a genetic counselor uses contracting to set a mutually beneficial agenda with a patient to guide the appointment. In a laboratory setting, a LBGC might use contracting to establish a realistic plan for case management with an ordering provider. Similarly, where a clinical genetic counselor may use communication skills to help a patient understand the benefits and limitations of genetic testing, a LBGC can use these same skills to assist an ordering physician in deciding upon an appropriate testing strategy.^{16,17} There are many other examples of shared skills between clinical and laboratory-based genetic counselors, which makes it reasonable for genetic counselors to transition between the two roles.

LBGC's report a high level of job satisfaction^{4,5}, which is one reason for what some in the field refer to as the "mass exodus" of clinical genetic counselors to the laboratory setting.¹⁹ Some reported aspects of this specialty that contribute to this satisfaction are autonomy, flexibility, opportunities for advancement, and feelings of being valued.^{4,5,20} Other reasons surmised for the transition from clinical genetic counselor to LBGC may include compassion burnout, financial incentives, and desires for new opportunities.^{19,20} Further research is planned in this area to assess how the increasing number of LBGC's is impacting the field of genetic counseling.¹⁹

2.1.2 Training

Genetic counselors are a type of healthcare professional with specialized education in both genetics and counseling who provide personalized care to patients and their families regarding matters of genetic health.¹⁴ Typically, genetic counselors have received a bachelor's degree in biology or a social science and then proceed on to more specialized training through a master's program in genetic counseling.²¹

The specialized education and training for genetic counselors began in 1969 with the formation of the first training program, and there are currently over 40 accredited genetic counseling programs in the United States and in Canada.^{22,23} These programs differ with regard to the specific coursework and clinical experiences offered, but to be accredited by the Accreditation Council for Genetic Counseling (ACGC) programs must meet certain accreditation standards.²⁴

Accredited genetic counseling programs are required to be, at minimum, two academic years in length.³ According to the ACGC's Standards of Accreditation for Graduate Programs in Genetic Counseling (2013), programs' curriculum should include, but not be limited to, the following content areas: principles of human genetics, applicability of related sciences to medical genetics/genomics, principles and practice of clinical/medical genetics, psychosocial content, social, ethical and legal issues in genetics, health care delivery systems and principles of public health, education, research methods, and professional development/self-care.

Additionally, students are required to have clinical and laboratory experiences and participate in a minimum of 50 "core cases", which develop the fundamental clinical counseling roles.³

The ACGC requirements for the 50 core cases are relatively structured and ensure that students have exposure to a variety of genetic conditions at various stages of life (preconception, prenatal, pediatric, and adult genetics) and gain experience in case management, patient education, and counseling roles.³ With regards to additional educational experiences, however, the ACGC guidelines are more vague, only citing the importance of exposure to multiple clinical and fieldwork settings and training that reflects current trends in the workplace.³ One such trend is the increasing number of genetic counselors employed in non-clinical roles.

A 2016 survey of 265 current genetic counseling students revealed that 66% were likely or very likely to pursue a non-clinical genetic counseling role at some point during their career²⁰, which indicates a potential need for formal and specialized training in non-clinical settings. Swanson et al. (2014) suggest that training programs introduce genetic counseling students to molecular databases such as ClinVar and HGMD, to facilitate their ability to critically analyze available literature to assess the functional importance of variants, and provide information about medical malpractice and federal and state laboratory regulations.¹⁸

Among LBGC's surveyed in 2016, 66.9% report at least some involvement in the supervision of genetic counseling students, but only 18.2% report that this is a frequent or major role.⁴ Unsurprisingly, the LBGC's who are associated with academic institutions are more likely to supervise students.⁴ Of note, no LBGC's who responded to this survey who worked in newborn screening, hospital send-out, or free fetal DNA laboratories reported supervising genetic counseling students, despite supervising other types of students and laboratory staff.⁴ These findings reveal a potential knowledge gap for genetic counseling students in the area of

laboratory genetic counseling and further highlight the need for additional learning opportunities in this specialty.⁴

Further complicating this issue are geographical and institutional limitations that make it difficult or impossible for some genetic counseling students to have direct contact with LBGC's.¹⁶ Given the relatively vague standards for laboratory experience, genetic counseling students are still able to satisfy the necessary requirements, but may not all be receiving similar training in this area. For example, some students have had the opportunity to spend an entire summer or clinical rotation block in laboratory genetic counseling, whereas others may have only a week or two total exposure to this area over the course of their training.¹⁶ Given the growing popularity of non-clinical genetic counseling roles, it is increasingly important standardize the type and amount of laboratory experiences that genetic counseling students receive, and provide equal opportunities for those students who do not have direct access to a laboratory through their genetic counseling program.

2.1.3 Accreditation Council for Genetic Counseling

The Accreditation Council for Genetic Counseling (ACGC), which was established in 2012 after separating from the American Board of Genetic Counseling (ABCG), is the accrediting body for genetic counseling programs in the United States and Canada. Their mission is to protect the integrity of the genetic counseling profession by establishing Standards for graduate level education.³ These Standards cover in detail the expectations for programs across three main areas: administration, curriculum and instruction, and evaluation.³

The administrative Standards refer to aspects of genetic counseling programs such as sponsoring institution involvement, qualifications for program directors and other program faculty and staff, and admissions.³ The curriculum Standards outline the basic coursework and clinical experiences that are required for students, including curriculum content, the Practice-Based Competencies, and the requirements for core cases.³ Some of these curriculum Standards have been described above in Section 2.1.2. The evaluation Standards require that program and student evaluation be a continual process and details the information that must be submitted for review on an annual basis.³

Particularly important to the current landscape of genetic counseling is the ACGC's curriculum requirement for training programs to provide their students with laboratory experience. More specifically, students must have instruction in, and observation of, genetic laboratory activities and ensure that students have the opportunity to interface with laboratory professionals.³ This experience is especially relevant given the increasing number of genetic counselors and genetic counseling students who are currently working in or are interested in working in non-clinical roles.^{5,18,20} In order to build competency with regard to laboratory work, it is suggested that programs offer opportunities to develop specifically useful laboratory-based skills (such as practice in variant interpretation)^{4,18}, rather than just requiring general "laboratory experience".

There are currently 37 accredited genetic counseling programs in the United States and four in Canada.²² Four additional programs in the United States are currently being reviewed for accreditation, and that number is expected to increase.²² Although ACGC accreditation is not mandatory for genetic counseling training programs, graduation from an ACGC accredited program is a requirement for an individual to obtain professional certification and licensure, which are often requirements for employment.^{21,23,25}

2.1.4 American Board of Genetic Counseling

The American Board of Genetic Counseling (ABGC) is the credentialing organization for genetic counselors in the United States and Canada.²⁶ This organization is responsible for the certification and recertification of genetic counselors, thereby protecting the public and fostering leadership and growth in the genetic counseling profession.²⁶ There are currently more than 4,000 ABCG certified genetic counselors.¹⁴

Though certification is a voluntary process, many employers require that their genetic counselor employees be board certified through the ABGC, which demonstrates competency and ensures that they have met standards necessary to provide quality genetic counseling services.^{21,23,25} Only students who have graduated from ACGC accredited programs may take the ABGC certification exam to become Certified Genetic Counselors (CGC®).^{24,27} Because many employers require certification, job opportunities for genetic counselors may be limited without this professional credential.²⁸

Due to the dynamic nature of the field, genetic counselors are required to recertify after five years.²³ There are two avenues for recertification: re-examination or the attainment of 12.5 continuing education units (CEU's).^{23,28} Recertification as a CGC® is a professional demonstration of an individual's commitment to continued education and maintenance of knowledge and skills.²⁸

The information that is on the certification examination is determined by the ABGC's Practice Analysis, which serves as the link between what is happening in the field and the exam content.²⁹ The Practice Analysis surveys genetic counselors to gauge the relevance of a variety of tasks associated with the profession to their current practice.²⁹ The tasks that are considered to be relevant inform the creation of the ABGC content outline, which is then used to write the

certification exam.²⁹ The ABGC content outline is published on the ABGC website and is available for genetic counseling students to use as a general study guide.³⁰

Since the findings from the Practice Analysis are used to write certification exam intended to demonstrate professional competency, they can also be useful in informing the development and evaluation of genetic counseling programs.²⁹ This way, ACGC accredited programs are not just effectively preparing their students to sit for the ABGC examination, but more importantly, providing them with practical knowledge that is relevant to current genetic counseling practice.

A number of studies^{4,15,16,18} that have been completed since the most recent Practice Analysis in 2011³⁰ and the 2016 NSGC Professional Status Survey⁵ have indicated significant growth in the area of genetic testing and genetic counseling involvement in the laboratory. Therefore, the material that is being taught in genetic counseling training programs and tested on the certification exam may need to be updated in order to more accurately reflect the current professional landscape. In fact, the ABGC sent out another Practice Analysis survey in the spring of 2017 and is currently in the process reviewing the collected data.³¹

2.1.5 Licensure

In addition to professional certification as a CGC®, some states require that their practicing genetic counselors be licensed.^{21,32} Because this requirement varies by state, not all professional organizations are in agreement about whether or not this should be mandatory. For example, the ABGC does not take an official position on licensure, whereas the NSGC and American Society of Human Genetics (ASHG) are in favor of it.^{32,33} Some arguments in favor of licensure are to

allow genetic counselors to independently order genetic testing, to allow genetic counselors to bill for their services, and like certification, ensure a competent workforce.³²

There are currently 20 states issuing licenses for genetic counselors, with four more states with bills that have been passed or are in rulemaking.³⁴ According to the NSGC's Guiding Principles for State Licensure, individuals should be credentialed as a CGC® by the ABGC before being granted a genetic counseling license.³⁵ It is therefore important that genetic counseling students graduate from an ACGC accredited program and achieve ABGC certification if they intend to practice as a genetic counselor in the following states: California, Connecticut, Delaware, Hawaii, Idaho, Illinois, Indiana, Kentucky, Massachusetts, Minnesota, Nebraska, New Hampshire, New Jersey, New Mexico, North Dakota, Ohio, Oklahoma, Pennsylvania, South Dakota, Tennessee, Utah, Virginia, and Washington.³⁴

In order to obtain professional credentials, like certification and licensure, a number of academic and professional prerequisites must be met, thereby demonstrating an individual's mastery of subject matter that is relevant to the field of genetic counseling. Because of the rapid growth of genetic testing and the expanding role of the genetic counselor, it is challenging for genetic counseling programs to stay up to date and offer training that is deeply specialized, such as full length rotations in laboratory settings. Therefore, in order to fill in potential knowledge gaps and provide unique learning opportunities for students, it is important to develop effective and efficient educational programs to supplement their genetic counseling training.

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2.2 ONLINE LEARNING

2.2.1 Background

Distance learning is not a new concept in education. In fact, Americans have participated in distance education (or correspondence education, as it was previously known) via the postal system since the late nineteenth century.³⁶ Distance learning evolved alongside technology and was made available through television, telephone, video, and eventually, the internet.³⁶

In response to the increasing demand for flexible and continuous education and training and the accessibility of technology, online learning is now mainstream.^{37,38} Some of the pressures that have spurred this growth include: the advance of globalization, the demand for lifelong learning, and the increasing costs of higher education.^{38,39}

In the past, distance learners were usually older and looking for opportunities to advance their careers.⁴⁰ Some of the early adopters of online learning were businesses looking for alternate forms of education for their employees, since knowledge has become a primary source of competitive advantage in many industries.^{36,41,42} In support of this, John Chambers, of Cisco Systems, once said: "The two great equalizers in life are the internet and education", so it is not surprising that businesses and universities have combined the two in an effort to empower their employees and students.⁴²

More recently, this type of education has been adapted to serve a diverse population including those with physical and learning disabilities, traditional college students, working parents, and lifelong learners.⁴⁰ Those interested in online learning often have significant personal and professional commitments that make it difficult to make traditional classroom

education their top priority.⁴⁰ Online learning provides students convenient and flexible options to satisfy their educational needs.

2.2.2 Benefits

Online courses are growing in number and popularity in part because of their ability to consolidate training across geographical and time constraints.^{7,36,40} In comparison to in-person learning, online education offers three distinct advantages: access, timeliness, and scalability.³⁸

Online learning can reach larger audiences than traditional in-person learning.³⁶ For example, it might allow for more students per class offering, without the space constraints of a brick-and-mortar classroom.⁴³ A 2012 study by Bowen et al. demonstrated that a blended course in undergraduate statistics used 56% less classroom space than the control group that was taught in-person.⁴³ This blended course offered most of its instruction online, but students met with instructors in-person once per week for an hour to ask questions or received targeted assistance.⁴³ If this finding is reproducible, it might be reasonable to say that universities could offer blended courses to more students per semester without the need for more classroom resources.

Another access benefit of online learning is that it has the potential to provide students with opportunities for learning that distance may have otherwise prohibited them from seeking out. For example, using the MedScape mobile application, physicians are now able to complete continuing medical education courses from their tablets and smartphones⁴⁴, which offers a convenient alternative to seeking out an in-person opportunity.

Because of the wide availability and accessibility of the internet, online learning allows students to satisfy their desire for additional education while minimizing the time spent away from their day-to-day responsibilities.³⁶ It may also be desirable to employers who want to

further educate their workforce without sacrificing time for travel to conferences and seminars. Additionally, since many online courses allow students to learn at any time and at their own pace, they may be a beneficial alternative for particularly motivated students who want to complete a course more quickly or for those with busy work, family, or personal schedules who may require extra time.^{36,40}

There is also evidence that online learning is a cost-effective alternative to traditional inperson learning.^{36,45} One reason for this is that it is almost always cheaper to educate a larger group of people at once rather than offering the course multiple times to smaller groups.⁷ Additionally, the majority of the costs associated with the implementation of an online course are upfront, with a minority being incurred later for maintenance and updates.^{7,43,45} This allows for providers of online learning experiences to scale up quite quickly and easily in response to growth and demand.

In an attempt to quantify the potential cost savings of a blended course, Bowen et al. (2012) ran illustrative cost simulations based on information from two public universities that took part in their study on a blended undergraduate course in statistics.⁴³ These cost simulations revealed that a carefully designed blended course could save a university between 19-57%.⁴³ However, these simulations were based on a number of variables including tenured instructor salaries, other faculty wages, class size, and number of in-person course meetings⁴³, so although there is potential, one cannot assume that all online or blended courses will result in cost savings.

2.2.3 Limitations

With the benefits of technology also come limitations, and online learning is no exception. Also, since there is not a "typical" online learning experience, there are limited successful models upon

which to build.^{36,37} As a result, many online learning experiences end up being "top down" teaching methods in which an instructor is simply transferring information to students.^{7,46} Though students may indeed be learning, such teaching methods may not be fostering critical thinking skills or a student's ability to incorporate new-found knowledge into their future professional practice.⁴⁶

Often, online learning modules fail to satisfy the needs of both the students and education providers.³⁷ While it seems like the goals of students and education providers could be complimentary, online education programs can miss the mark by implementing a course that is not well conceptualized.³⁷ For example, in addition to the perception that they have indeed learned the material, students also seek a satisfying online education experience.³⁷ Education providers, on the other hand, focus their measurements of success on improved student performance.³⁷ One way to achieve balance could be for education professionals to consider a user-centered design and provide learning materials and practice for real world situations that their students might encounter.^{36,37} Appreciating the audience is important in designing an effective and enjoyable course.⁷

Because online learning is vulnerable to the often perceived anti-social nature of technology, it is recommended that online education providers take extra care to build and foster a learning community in their course or training program.³⁷ There is a social aspect to learning that should be considered in online education just as it is in a traditional classroom.^{7,36} As suggested by educators, successful online learning is an interactive experience and not simply a web-based tutorial or online textbook.³⁷ To address this, online educators will often implement compulsory participation activities, such as a set number of discussion board posts. Unfortunately, these can result in forced, asynchronous dialogue among students, forcing them down a predetermined path to the "correct answer", rather than allowing for organic discussion.⁴⁶

Critics suggest that these kinds of activities create conformists rather than critical thinkers.⁴⁶

It is also possible that the threat of assessment that prompts students' posts, rather than a true desire to participate.⁴⁷ In 2003, Fox and MacKeogh published a study on the effectiveness of two pedagogical methods (online resource/debate and peer-tutoring) in facilitating higher order learning in an undergraduate developmental and educational psychology course. In both methods, it was concluded by thematic analysis of discussion board posts that the students were in fact, engaging in higher order learning (analyzing, evaluating, and creating), but that the overall participation was notably lacking.⁴⁷ Only 75% of the 12 students in the online resource group and 46% of the 13 students in the peer-tutoring group participated on the discussion board at any point during the course.⁴⁷ The recommended participation was four posts per week, but the groups averaged 6.6 and 4.8 posts, respectively, over the entire duration of the 10-week course.⁴⁷ Though some students claimed technical difficulties or personal issues as reasons for their lack of participation, the authors surmise that because participation was not part of the graded course assessment, students did not have an incentive to join in the discussion. In fact, one participant was reported to have said that she did not see a point in putting in the work as it had nothing to do with the assessment.⁴⁷

Because of the lack of in-person instructor support, online students must be particularly dedicated, self-motivated, and proactive.⁴⁰ Just as in a traditional classroom, though, students who participate in online learning also have a variety of learning styles, and some learning styles are more suited for this type of education.⁷ It is important that online educators take extra care to ensure that students feel as supported as possible in their particular learning style.⁷ In a traditional education setting, it is easier for a good teacher to assess a classroom⁴⁶ and identify students who may require extra help, but this can be much more difficult online.

Although there are some education providers who provide entire degree programs via online learning, this may not always be appropriate for the subject matter being taught. In many cases, online learning cannot compete with, nor completely replace in-person learning, but rather could be used to enhance it in a blended approach.^{7,42,48,49}

2.2.4 Effectiveness

Numerous publications exist about the effectiveness of online learning, but it appears that the literature is replete with articles that have small sample sizes, lack of control groups, and other flaws in study design that cloud their usefulness in contributing generalizable information. Furthermore, there are many different ways that online learning can be applied and online courses are implemented for a number of reasons for a number of learner populations. It is therefore difficult to assess the effectiveness of online learning as a whole, as the outcomes are very often situational.

A current trend in online learning is the method of blended learning, in which a course has both online and in-person components. Blended learning is a way to achieve some of the benefits of online learning, such as timeliness and accessibility, while avoiding known limitations, like student isolation and lack of instructor support.⁵⁰

A relatively large randomized control study by Bowen et al. (2012) set out to determine the effectiveness of an introductory course in interactive physics when delivered in traditional and blended formats. This study included 605 undergraduate students from across six public universities who were randomized into either the traditional or blended version of the course.⁴³ In the blended course, most of the instruction was online, but was supplemented with once weekly in-person sessions for questions and assistance.⁴³ As a measure of knowledge, students were asked to take the CAOS statistical literacy test at the start and end of the course.⁴³ Additionally, student scores on a final exam for the course and successful completion (passing) of the course were also considered.⁴³ The results of this study showed that on average, students in the blended course learned just as much as those in the traditional course.⁴³

There is also evidence to suggest that online learning may actually be more effective than in-person learning due to the ability to break the material up over several sessions and to allow the learner to structure their own learning.^{51,52} If the online learning experience is set up in such a way that the learner has the opportunity to revisit the learning material, there are more opportunities for content reinforcement.⁵¹ This could allow the learner to quickly refresh their knowledge on topics that they are comfortable with and spend more time on the topics that they find challenging.

Interestingly, the study by Bowen et al. (2012) demonstrated that the students in the blended course were able to achieve comparable outcomes to those in the traditional course in one fifth less of the time.⁴³ These results compared favorably with a smaller, randomized case control study conducted in 2007 among 60 students in an introductory physics course.⁵³ Similarly to Bowen et al. (2012), students were randomized to either a traditional or hybrid class format, but in this study, the hybrid class was accelerated and met for only 8 weeks instead of 15.⁵³ This study showed that students in the accelerated hybrid model performed just as well as the students in the traditional course on in-class examinations having learned the material in half the time.⁵³ The results of these two studies suggest that online learning in a blended format may actually be more effective than traditional in-person learning.

Another current trend in online learning is a focus on a more student-centered, or constructivist approach in which students build new knowledge on top of their previous work and life experiences.^{54,55} In this type of learning environment, the instructor is more of a coach or

facilitator, guiding students through discussions and problem-solving exercises, allowing students to take an active role in their learning.⁵⁵ This approach to education is particularly effective because learning activities are often centered around real-world examples⁵⁵, and students tend to learn better when they are invested in the subject matter.⁵⁶

Literature reviews on continuing medical education (CME) for physicians suggest that in order for learning experiences to be effective, they must not simply have lecturers "shouting out of windows"⁵⁷, but rather engage students in participation in learning subject matter that is relevant to them.^{56,58,59} Though many papers do not explicitly state a specific learning model, their methods often utilize constructivist principles. This model is particularly useful in educating medical professionals as the desired outcome is to impart relevant knowledge that can be easily recalled and ultimately utilized in professional practice.⁵⁹ Online learning experiences that engage the learner and exhibit real-world relevance can be just as effective as in-person learning, and in fact, lead to sustained gains in knowledge and measurable changes in behavior.^{51,59}

2.3 ONLINE LEARNING FOR HEALTH PROFESSIONALS

2.3.1 Genetic Counselors

Online education is not new to the genetic counseling profession. For a number of years, the National Society of Genetic Counselors (NSGC) has offered a variety of online education experiences that have been approved for continuing education units (CEU's), which are required for receritification.⁶⁰ While NSGC states that these online education experiences cannot replace
the in-person learning experiences at the NSGC Annual Education Conference, it does quote three distinct benefits of their courses that are congruent with benefits of online learning in general: convenience (courses are available any time), increased information retention (due to a learn-at-your-own-pace format), and lower overall cost (no travel or formal instructor).⁶⁰ Despite online education being widely available to genetic counselors, there is a lack of targeted literature available to describe the use or effectiveness of online learning for this specific population.

One related study published in 2013 by Pustilnick, et al., demonstrated that an online course in basic genetics and genetic counseling was effective in increasing knowledge in a small group of Brazilian psychologists.⁴⁹ In this study, psychologists with no prior professional activity in the area of genetic counseling were given a test of knowledge prior to the start of the course, participated in a completely online, five-week course, and then took the same test of knowledge immediately after the conclusion of the course.⁴⁹ There was a statistically significant increase in knowledge when comparing post-course test scores to pre-course test scores, confirming that this online module is an effective alternative for educating this particular population of health care provider about genetic counseling.⁴⁹

This genetic counseling provider population differs notably from the United States and Canada, because in Brazil, genetic counseling is considered to be a multidisciplinary approach, involving biologists, physicians, and psychologists, with the latter playing a crucial role in the emotional support of patients.⁴⁹ In the United States and Canada, genetic counseling functions as its own unique profession in which providers specialize in the education and emotional support of their patients regarding matters of genetic health. Regardless of the differences between these groups, this study yields promising results for the use of online learning as an option to educate health care professionals about genetic counseling.

Despite the lack of literature on the effectiveness of online learning for genetic counselors specifically, there are two genetic counseling programs, the University of Arkansas for Medical Sciences and Bay Path University, that are taking advantage of the reported benefits and effectiveness of online learning.

The University of Arkansas for Medical Sciences (UAMS) offers a master's program in genetic counseling in which most of the coursework is blended with both live instruction and online components.⁶¹ The UAMS program also provides the opportunity for students to take their clinical rotations at off campus sites due to the ability to attend classes via interactive video conferencing.⁶¹ Their curriculum also places a strong focus in telegenetics.⁶¹

The Bay Path University master's in genetic counseling program, set to launch their first class in the fall of 2017, advertises their coursework as flexible and blended, by offering classes online and on-campus on the weekends.⁶² Their program director, Ms. Nancy Steinberg Warren, MS, CGC, has been particularly involved in online genetics education, having developed an online education module for speech language pathologists and audiologists (Genetics in the Practice of Speech-Language Pathology and Audiology) and also the Genetic Counseling Cultural and Linguistic Competence Toolkit, and online resource portal for health professionals.⁶² Additionally, in recognition of the growing role for genetic counselors in industry, the Bay Path program has established clinical rotation positions for its students with Myriad Genetics and Quest Diagnostics and anticipates the addition of other similar sites in the future.⁶²

2.3.2 Other Health Professionals

Advances in medicine are rapid, and traditional education systems are having difficulty keeping pace⁴⁹, leaving the possibility that the knowledge that health care providers possess can quickly become out of date.⁶³ There is even some evidence to suggest that there is an inverse relationship between physician practice length and quality of care provided, further validating the necessity of continuing medical education (CME).⁶³ Therefore, continuing education opportunities for health professionals must be dynamic in order to address this issue.⁴⁹ As early as 1992, physicians recognized the potential for computer-based learning, and implemented it for their CME requirements.⁵⁸ Today, many types of health professionals in the United States use online learning for their continuing education with demonstrated effectiveness.^{49,51,64}

A 2005 publication by Fordis et al. showed that the knowledge gains of 97 primary care physicians who took an online CME course regarding the management of patients with lipid disorders was significant and comparable to a similar CME course that was given in person. In this study, knowledge assessments were conducted immediately prior to the course, immediately after the course, and 12 weeks after the course, confirming that an online approach to CME is effective in facilitating sustained knowledge gains of approximately 30%.⁵¹ Additionally the physicians who participated in the online CME course revealed a significantly increased change in behavior on the part of the provider in treating patients according to established guidelines⁵¹, a result that has been well-documented as difficult to achieve using more traditional CME methods.^{65,66}

A large 2015 study by Lubarda et al. reported statistically significant gains in knowledge among 901 neurologists and psychiatrists regarding the management and pathophysiology of Parkinson's disease psychosis (PDP) after the completion of an online CME course. Knowledge assessments were given prior to the course and immediately after the course and both neurologists and psychiatrists achieved higher scores after the completion of the course.⁴⁴ Neurologist participants increased their knowledge regarding the management of PDP by 15-17% and increased their knowledge of PDP pathophysiology by 9%.⁴⁴ Psychiatrist participants achieved similar results, increasing their knowledge regarding the management of PDP by 18% and their knowledge of PDP pathophysiology by 7%.⁴⁴ Of note, this CME activity was available to participants on a variety of platforms, including personal computers, tablets, and smart phones via the Medscape Mobile application to ensure real-time access.⁴⁴ The success of this method in educating its participants demonstrates the growth of online education and the convenience with which it can be delivered.

In addition to use for continuing education for practicing health professionals, online learning is now also being regularly used for the education of students in the health sciences.^{48,56,67} There are a number of different types of online learning available to medical students, including synchronous courses, in which students engage in a course at a predetermined time, asynchronous courses, in which students can learn at their own pace, as well as repositories like the MedEdPortal, in which students can access photographs, videos, tutorials, and other learning materials at their leisure to supplement their studies.⁵⁶

An example of a successful asynchronous course in the health sciences is a 2017 publication that demonstrated the effective use of online education materials in increasing knowledge among medical residents and medical and pharmacy students.⁶⁸ In this study, students were recruited to participate in an interactive online module regarding the proper use of antibiotics to treat common upper respiratory infections.⁶⁸ Participants were given a 12-question quiz to measure their baseline knowledge prior to the series, and then the same quiz was given to them immediately post-module and then again after 2 months.⁶⁸ Only 32 participants completed

the study in its entirety, but compared to the baseline scores, the results showed a 43% average increase in scores immediately after online module and a 20% average increase in scores at the 2-month follow-up, demonstrating that the module was effective in increasing participant knowledge with modest retention after 2 months.⁶⁸

Of particular use to medical students are online courses that are blended with traditional in-person learning.^{56,67,69–71} Course directors are increasingly using computer-based modules and suggesting them as study aids to increase their students' long-term retention of the anatomical sciences, since curricula hours in this area are decreasing.^{69,70} Supporting the idea of blended learning, a 2016 study by Salajegheh et al. showed that an online module in radiological interpretation, when completed in conjunction with a standard medical school training course, was effective increasing student knowledge and skills. Participants in this study were medical students from the Griffith University Bachelor of Medicine/Bachelor of Surgery program that were split into two groups: a control group of 66 second year students that participated in the formal radiological training course only, and an intervention group of 57 first year students that participated in the formal course and also an online training module that they could access at their own pace.⁶⁹ Despite being a year behind in medical training, the intervention group scored almost 10% higher on a radiological interpretation quiz than the second year students who did not participate in the online module.⁶⁹ Additionally, a follow-up assessment a year later showed sustained knowledge gains.⁶⁹ This study highlights the benefits of blending online education opportunities with traditional in-person coursework.

In addition to being effective in increasing student knowledge, there is also evidence to suggest that online education programs can also be used to enhance clinical skills with overall satisfaction on the part of the students/participants.⁷¹ One popular online learning resource is DocCom, which features 42 interactive learning modules to help teach communication skills to

health professionals.⁷² DocCom is used by more than 22,000 people across 75 learning institutions in 9 countries.⁷²

A 2010 study evaluated the effectiveness of an online clinical skills assessment tool for a group of 55 medical interns in the Drexel University College of Medicine with a focus on presenting bad news to patients.⁷¹ As a baseline assessment, all students participated in a webbased interaction with a standardized patient and a project coordinator filled out a behavioral assessment checklist.⁷¹ The students were then divided into three study groups: a control group that received no educational intervention, a group that participated in a DocCom online education module, and a group that participated in a DocCom online education module and also had a second web-based interaction with a standardized patient who offered feedback.⁷¹ After the educational intervention (or lack thereof for the control group), the students participated in another web-based interaction with a standardized patient who offered feedback and a project coordinator filled out a behavioral assessment.⁷¹ All three study groups demonstrated increased scores on their behavioral assessments.⁷¹ The control group's average score increased by 8%, the group that participated in an online webinar module increased their average score by 14%, and the group that participated in an online webinar module and had an extra web-based interaction with a standardized patient increased their average score by 27%.⁷¹ Both groups that participated in the online webinar module submitted feedback and a majority felt that the module was effective in increasing their knowledge and was a good use of their time.⁷¹

Though this study demonstrates that the online learning tool was effective in increasing students' scores on behavioral assessments, the success was based on the addition of learning components; as students had additional opportunities to practice their skills, their scores improved. There was no evaluation of a comparable in-person experience. Similar issues were encountered by McCutcheon et al. (2014) in their effort to evaluate the effectiveness of online

learning experiences for nursing students to develop clinical skills. Though 13 papers suggested that nursing students obtained comparable or higher levels of clinical skill after participating in online learning experiences, McCutcheon et al. (2014) point out that there were not fair comparisons with traditional in-person experiences. For example, there were no time or access limits on the online modules, so students may have simply had more time and resources to aid in learning as compared to control groups.⁷³ Without more carefully designed studies, these findings can only suggest that the development of clinical skills in an online learning environment may be best used when blended with in-person experiences.

2.4 SUMMARY AND RATIONALE FOR PROJECT

In order to become a board certified and licensed genetic counselor, there are a number of academic and professional requirements that an individual must satisfy, beginning with the graduation from an ACGC accredited training program.^{3,27,35} In doing so, students demonstrate their mastery of a standardized curriculum relevant to the current climate of the genetic counseling profession.³

Laboratory work is rapidly growing area of interest for genetic counselors, and more than 10% report that it is now a primary area of their work.⁵ This highlights the importance of the ACGC's requirement for genetic counseling students to obtain laboratory experience³, and supports the development of concentrated coursework in this particular specialty.

The demonstrated effectiveness of online learning for medical professionals^{49,51,64} and medical students^{48,71} and the NSGC's endorsement of online courses for continuing education⁶⁰ support the development and evaluation of an online learning experience to educate genetic

counseling students about the laboratory applications of genetic counseling. If shown effective, such a course could be a valuable resource to genetic counseling students and could aid program directors in their efforts to satisfy the ACGC's requirement for laboratory experience.³

3.0 MANUSCRIPT

3.1 ABSTRACT

Due to the growth of genetic technology, genetic counseling training programs are challenged with building a foundation of knowledge in a constantly evolving field. As a result, there is a struggle to incorporate more educational content into training programs to ensure students' success as practitioners without increasing the overall length of training programs.

GeneDx, a commercial laboratory, has been involved in the training of students interested in learning more about the laboratory applications of genetic counseling. In the past, they had welcomed students onsite to gain this experience, but with the increased demand for clinical placements with ACGC's requirements for all genetic counseling students to have laboratory experience, the requests for placements have outweighed GeneDx's ability to accommodate all interested students. To meet the needs of those unable to rotate on site, GeneDx created an eight-week webinar series highlighting the unique role of a genetic counselor in the laboratory setting. This series included seven lectures and one panel discussion.

The purpose of this project was to evaluate the effectiveness of the GeneDx webinar series in educating genetic counseling students about the laboratory applications of genetic counseling as well as the satisfaction of both the students and program directors with the series.

Pre and post-lecture quizzes were used to assess students' knowledge of the material contained in the seven lectures. Paired t-tests identified statistically significant increases in

knowledge for four of the seven lectures ($\alpha = 0.05$). Post-lecture and post-series satisfaction surveys were also administered to gauge participant satisfaction. These results indicate that genetic counseling students and program directors felt that this was a positive learning experience.

This project is of public health significance due to the increasing demand for and availability of genetic testing, which is often facilitated by a genetic counselor. In order to meet the needs of a growing patient population with an increasing array of genetic testing options, it is important that genetic counseling students have specialized training in the laboratory applications of the profession prior to entering into the field.

3.2 BACKGROUND

3.2.1 Genetic Counseling

Genetic counselors are healthcare professionals with specialized education in both genetics and counseling who provide personalized care to patients and their families regarding matters of genetic health.¹⁴ Typically, genetic counselors have received a bachelor's degree in biology or a social science and then proceed on to graduate training in a program that is usually two years in length.³ Genetic counselors work in a variety of clinical and non-clinical settings such as private hospitals, university-based medical centers, private practice, and industry, and opportunities continue to emerge.¹² Like other health professionals, genetic counselors can provide general care or can specialize in specific areas such as pediatrics, cancer, neurology, and more.¹⁴

In order to become a board certified and licensed genetic counselor, there are a number of academic and professional requirements that an individual must satisfy, beginning with the graduation from an Accreditation Council for Genetic Counseling (ACGC) accredited training program.^{3,27,35}The ACGC is the accrediting body for genetic counseling programs in the United States and Canada whose mission is to protect the integrity of the genetic counseling profession by establishing Standards for graduate level education.³ By graduating from an ACGC accredited program, students demonstrate their mastery of a standardized curriculum relevant to the current climate of the genetic counseling profession.³

Particularly important to the current landscape of genetic counseling is the ACGC's curriculum requirement for training programs to provide their students with laboratory experience. More specifically, students must have instruction in, and observation of, genetic laboratory activities and ensure that students have the opportunity to interact with laboratory professionals.³ This experience is especially relevant given the increasing number of genetic counselors and genetic counseling students who are currently working in or are interested in working in non-clinical roles.^{5,18,20}

3.2.2 Laboratory-Based Genetic Counseling

Due to the increasing number of available genetic testing services, a growing number of genetic counselors are specializing in laboratory work to some degree⁴. In fact, 10.2% of genetic counselors who responded to the National Society of Genetic Counselors (NSGC) 2016 Professional Status Survey now report laboratory work or genetic testing as a primary area of work.⁵ For the subset of genetic counselors who do not counsel patients, 31% claim that genetic

testing is their primary specialty.⁵ These figures have increased by 5% and 2.8% respectively since the NSGC's last Professional Status Survey in 2014.⁷⁴

Laboratory-based genetic counseling is a relatively new specialty. A 2016 study of 121 laboratory-based genetic counselors (LBGC's) by Waltman et al. found that the mean length of employment in a laboratory was 4.3 years and that almost one fifth of those individuals were the first LBGC in their company.⁴ Because this specialty is so new, a number of studies have been done to try to define the scope of practice of a LBGC, which will aid in the development, expansion, and exposure of LBGC positions.^{4,15–18}

Building on the work of Christian et al. (2012)¹⁵, Waltman et al. (2016) set out to further define the role of the laboratory genetic counselor and assess the activities that they perform on a day-to-day basis.⁴ Of all reported job activities, the one that LBGC's reported as spending most of their time performing was customer liaising/case coordination (30.2% of their time).⁴ The second highest percentage of LBGCs' time (26.1%) was reportedly spent on results interpretation and reporting.⁴ These results were corroborated by the findings of Christian et al. (2012).^{4,15}Other documented responsibilities of LBGC's included sales and marketing, counseling patients, research, management, test development and performance, website and database support, education and supervision of students, and insurance and billing.⁴ Though these tasks accounted for less than 10% of a LBGC's time each⁴, they demonstrate the breadth and depth of the role of the LBGC.

In order to build competency among genetic counseling students with regard to laboratory work, it has been suggested that genetic counseling programs offer opportunities to develop specifically useful laboratory-based skills (such as practice in variant interpretation)^{4,18}, rather than just requiring general "laboratory experience". One way to achieve this would be for programs to offer laboratory rotations as part of their curriculum. For example, Bay Path

University has cultivated relationships with at least two genetic laboratories in order to encourage their genetic counseling students to participate in a formal laboratory rotation.⁶²

Another interesting feature of the Bay Path University program, as well as the UAMS program, is their use of blended learning.^{61,62} These two programs advertise that much of their coursework can be completed online in order to provide their students with flexible learning opportunities, thereby allowing their students to choose the clinical rotations that are most interesting and convenient to them, even if they may be far away.^{61,62}

Although there is a dearth of literature on the subject, it could be speculated that one barrier to the widespread adoption of online learning in genetic counseling programs might be a lack of evidence demonstrating its effectiveness for this specific group. However, the reported effectiveness of online learning for medical professionals^{49,51,64} and medical students^{48,71} and the NSGC's endorsement of online courses for continuing education⁶⁰ support the development and evaluation of an online learning experience to educate genetic counseling students about the laboratory applications of genetic counseling. If shown effective, such a course could be a valuable resource to genetic counseling students and could aid program directors in their efforts to satisfy the ACGC's requirement for laboratory experience.³

3.2.3 GeneDx Webinar Series

In the past, GeneDx, a commercial genetic testing laboratory based in Gaithersburg, Maryland, had welcomed genetic counseling students on-site for a few weeks each year in order to introduce them to laboratory technologies and the role that a counselor can play in the laboratory setting. In recent years however, the demand for such placements has outweighed GeneDx's ability to accommodate all interested students. In order to provide more students with laboratory

experience, GeneDx created an eight-part webinar series entitled "Behind the Scenes: Lessons from Laboratory Genetic Counselors" in which a genetic counselor presents a lecture and leads a discussion on a variety of topics.

This webinar series included seven lectures designed to highlight some applications of genetic counseling skills to non-clinical work and included topics such as the use of psychosocial skills in a laboratory setting, things to consider when ordering genetic testing, and variant classification and interpretation. The eighth and final webinar in the series was a panel discussion, which consisted of four GeneDx genetic counselors sharing their unique and specialized roles within the company, and the professional experiences that lead them to their current positions.

The webinars were held live at a predetermined time once per week, and students joined in via the Adobe Connect software for the video component and JoinMe for the audio component. These platforms were selected in order to facilitate participation through features like real-time chat, video sharing, and conference-style conversation. Although the webinar project team appreciated the convenience of recording the series for students to view at their leisure, it was decided that the series should be offered live in order to promote interactivity and among lecturers and students.

By offering this webinar series remotely, more students are able to participate in this experience than would otherwise be reasonable due to time and geographical constraints. In addition to this benefit, there is also evidence to support that online learning is as effective in educating students as traditional in-person learning.^{6,7} Research on this subject has been done for some applications of distance learning in business and some medical professions, but to our knowledge, not specifically for the population of genetic counseling students.

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The goal of this project was two-fold. Because there is increasing emphasis on evidencebased education programs⁸, the first goal was to determine the effectiveness of this pedagogical approach in educating genetic counseling students about the laboratory applications of genetic counseling. The second goal was to assess genetic counseling students' and program directors' satisfaction with the course to evaluate whether they found the webinar series to be worth the investment of their time. If the GeneDx webinar series was found to be an effective approach in educating students and students as well as program directors were satisfied with the series, then perhaps this approach can be used to incorporate more content into training programs in an efficient way.

3.3 METHODS

3.3.1 IRB Review

This project was reviewed by the Institutional Review Board of the University of Pittsburgh and deemed to not be research (PRO17040315 - APPENDIX A).

3.3.2 Student Population

Prior to the start of the Fall 2016 and Spring 2017 offerings of the series, the team that developed the GeneDx webinar series contacted the program directors of seven genetic counseling programs by email to gauge their interest in having their students participate in the series. These seven programs were selected either because they had reached out to GeneDx in the past for educational opportunities or because a member of the webinar team was affiliated with that program. Five of the seven program directors expressed interest and supplied the names and email addresses of their students who were interested in participating. The two program directors who were not interested in participating in the Fall of 2016 or Spring of 2017 both said that they would be interested in future offerings of the webinar series.

The webinar team then contacted the interested students by email with details of the webinar series and provided them the information necessary to join the webinars, which were scheduled once per week. Throughout the series, students were emailed once a week with information pertinent to that week's lecture, including copies of the lecture notes.

A total of 41 students expressed interest in participating, and 36 students eventually participated in at least one lecture. Not all students from each of the schools participated and students were not required to attend every webinar in the series.

Prior to a student's first lecture, demographic data were collected via the University of Pittsburgh's Qualtrics software for the purposes of identifying trends in the study data. Not all of the students provided responses to all demographic questions, as these did not require responses from individuals. The mean values for each demographic category were calculated using only the number of individuals who responded to that particular question. The demographic data can be found in Table 1.

In order to follow responses throughout the webinar series, students were asked to develop a Participant Identification Number (PIN), using a prefix of the first letter of their home institution followed by a six-digit number of their choosing. The prefixes used in the Fall 2016 series were: "E" for Emory University and "P" for the University of Pittsburgh. The prefixes used in the Spring 2017 series were: "B" for Boston University, "I" for Indiana State University, and "S" for Sarah Lawrence College. A hypothetical example of a PIN for a student from the University of Pittsburgh could be: "P123456".

Students were not required to attend each lecture, but after observing some degree of attrition in the Fall 2016 course, the webinar team decided to take attendance in the Spring 2017 course. In order to list the GeneDx webinar series on their resumes, the webinar team asked that students participate in at least four lectures. Participation in each of the lectures can be found in Table 2.

3.3.3 GeneDx Webinar Series

The title given to the GeneDx webinar series is "Behind the Scenes: Lessons from Laboratory Genetic Counselors". This eight-part webinar series is comprised of seven lectures and one panel discussion:

- Week 1: Lecture 1 The Role of a Genetic Counselor at GeneDx
- Week 2: Lecture 2 Things to Consider When Ordering a Test
- Week 3: Lecture 3 Application of Psychosocial/Managerial Skills in the Lab
- Week 4: Lecture 4 Tools Used in Variant Interpretation
- Week 5: Lecture 5 Tools Used in Variant Interpretation, Part II & Anatomy of a Report
- Week 6: Lecture 6 Whole Exome Sequencing: Secondary and Incidental Findings
- Week 7: Lecture 7 Incidental and Unique Findings
- Week 8: Panel Discussion

The webinars were held live at a predetermined time once per week, and students joined in via the Adobe Connect software for the video component and JoinMe for the audio component. For detailed course syllabi including lecture topics and speakers, see Appendices B and C.

3.3.3.1 Pre and Post-Lecture Quizzes

Prior to the Fall 2016 offering of the webinar series, the primary author was given the seven webinar lectures from the GeneDx team members in order to draft knowledge-based multiple choice questions to be used for the pre and post-lecture quizzes. The webinars were reviewed and questions were written based on the main points of each lecture. The questions underwent multiples rounds of revision from the other members of the webinar team until a consensus was reached. Four to five questions were agreed upon for each lecture and uploaded to the University of Pittsburgh's Qualtrics software. These questions can be found in Appendix F.

Approximately 24 hours prior to the start of each of the seven lectures, the webinar team emailed out a link via the Qualtrics software to the online, four to five multiple-choice question quiz pertaining to that lecture's content. All pre and post-lecture quiz questions were required to have answers selected by students. Immediately after the conclusion of each lecture, the webinar team emailed out the post-lecture quiz, which contained the same questions as the pre-lecture quiz. The purpose of the pre and post-lecture quizzes was to measure any potential change in student knowledge as a result of the lecture.

3.3.3.2 Post-Lecture Satisfaction Surveys

Prior to the Fall 2016 offering of the webinar series, the primary author drafted satisfaction questions to be used for the post-lecture surveys. The questions underwent multiples rounds of revision from the other members of the webinar team until a consensus was reached. When the questions were agreed upon, they were uploaded to the University of Pittsburgh's Qualtrics software. These questions can be found in Appendix G.

After of each of the seven lectures, the webinar team emailed out the satisfaction survey via the Qualtrics software in conjunction with the post-lecture knowledge questions to collect

student feedback on that day's lecture, including satisfaction with the lecturer and lecture content. These survey questions were a mixture of Likert-scale questions as well as open-ended questions that allowed the student a free-text response. No post-lecture satisfaction question required a response from participants. The purpose of the post-lecture satisfaction surveys was to assess satisfaction with the lectures and to collect feedback for future improvement of the webinar series.

3.3.3.3 Post-Series Satisfaction Surveys

Prior to the Fall 2016 offering of the webinar series, the primary author drafted satisfaction questions to be used for the post-series survey. The questions underwent multiples rounds of revision from the other members of the webinar team until a consensus was reached. When the questions were agreed upon, they were uploaded to the University of Pittsburgh's Qualtrics software. These questions can be found in Appendix H.

At the conclusion of the webinar series, the webinar team emailed the post-series satisfaction survey via the Qualtrics software to the students to collect their feedback on the series overall. A separate, shorter survey, which can be found in Appendix I, was emailed to the program directors of the participating schools to collect their feedback. These survey questions were a mixture of Likert-scale questions as well as open-ended questions. No post-series satisfaction question required a response from individuals. The purpose of the post-series satisfaction surveys was to determine satisfaction with this learning experience and to collect feedback for future improvement of the webinar series.

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3.3.4 Analysis

3.3.4.1 Pre and Post-Lecture Quizzes

The responses from the Fall 2016 and Spring 2017 course were combined and analyzed together. The differences in post versus pre-lecture scores were generated for each of the seven lectures, plotted as histograms, and found to be either normally or approximately normally distributed. Each of the seven lectures was analyzed for a statistically significant difference in scores using a paired t-test ($\alpha = 0.05$ level of significance) in the StataSE software, version 14.

3.3.4.2 Post-Lecture Satisfaction Surveys

Each of Likert-scale satisfaction responses was converted to a five-number score, where a strong negative response is equal to one and a strong positive response is equal to five, and then the average score per question was calculated. The open-ended responses were grouped according to content and general themes were generated to focus efforts for future course improvement. The responses from the Fall 2016 and Spring 2017 course were analyzed together, with the exception of two questions: "*Please rate the quality of the speaker*" and "*Please rate the clarity with which the information was presented*". Because these two questions were dependent on the individual lecturer, the data were generated and shared with the GeneDx to provide the lecturers with personal feedback.

3.3.4.3 Post-Series Satisfaction Surveys

Each of Likert-scale satisfaction responses was converted to a five-number score, where a strong negative response is equal to one and a strong positive response is equal to five, and then the average score per question was calculated. The open-ended responses were grouped according

to content and general themes were generated to focus efforts for future course improvement. The responses from the Fall 2016 and Spring 2017 course were analyzed together.

3.4 **RESULTS**

3.4.1 Students

In total, 41 students from five genetic counseling programs were contacted by email with information regarding the GeneDx webinar series and by reviewing the number of unique PIN's, it was determined that a total of 36 students participated across both offerings of the course. This yields a participation rate of 87.8% of students contacted. Not all students participated in each lecture.

In the Fall 2016 offering of the GeneDx webinar series, 16 second year genetic counseling students from Emory University and the University of Pittsburgh participated. In the Spring 2017 offering of the GeneDx webinar series, eight first year and 12 second year genetic counseling students from Boston University, Indiana State University, and Sarah Lawrence College participated.

The majority of students were second year genetic counseling students (77.8%) whose highest level of education prior to beginning their program was a BA/BS (86.1%). 52.8% of students had some amount of working laboratory experience prior to starting their genetic counseling program, and 77.1% had not had any laboratory experience as part of their clinical rotations for their genetic counseling program. The complete list of demographics for the students can be found in Table 1.

| | N = 36 |
|----------------------------|------------|
| | n (%) |
| Learning Institution | |
| Boston University – | 5 (13.9%) |
| Emory University – | 7 (19.4%) |
| Indiana State University - | 4 (11.1%) |
| Sarah Lawrence College - | 11 (30.6%) |
| University of Pittsburgh - | 9 (25%) |
| | |
| Year in Program | |
| 1 st Year - | 8 (22.2%) |
| 2 nd Year - | 28 (77.8%) |
| | |
| Mean Age | 25.6 years |
| | |
| Highest Level of Education | |
| BA/BS - | 31 (86.1%) |
| MS - | 3 (8.3%) |
| MD or PhD - | 2 (5.6%) |

Table 1: Student Demographics

Table 1 (Continued)

| Mean Undergraduate Laboratory Courses | 7.69 |
|---|------------|
| | |
| Mean Graduate Laboratory Courses | 1.08 |
| | |
| Laboratory Experience | |
| Yes - | 19 (52.8%) |
| No - | 17 (47.2%) |
| | |
| Mean Laboratory Experience | 3.89 years |
| | |
| Laboratory Rotation | |
| Yes - | 8 (22.2%) |
| No - | 28 (77.8%) |
| | |
| Mean Length of Laboratory Rotation | 4.32 weeks |
| | |
| Interest in Laboratory Genetic Counseling | |
| Very Interested - | 3 (8.3%) |
| Interested - | 14 (38.9%) |
| Neutral - | 16 (44.4%) |
| Disinterested - | 3 (8.3%) |
| Very Disinterested - | 0 (0%) |

During the first lecture of the second offering of the series in the Spring 2017, there was a possible error in the survey logic, and the number of years of laboratory experience was not recorded for the nine students who documented that they had worked in a laboratory outside of

undergraduate or graduate coursework. Therefore, the average length of time worked in a laboratory, 3.89 years, was calculated without including these nine students.

Not all of the students who were documented as having participated in the lecture by completing the pre-lecture quiz ended up completing the post-lecture quiz, as shown in Table 2. Only participants whose PIN was linked to a pre-lecture and post-lecture response for knowledge-based questions were used for analysis.

| | Fall 2016 | Spring 2017 | Total | Fall 2016 | Spring 2017 | Total |
|-----------|--------------|--------------|--------------|--------------|--------------|--------------|
| | Participants | Participants | Participants | Participants | Participants | Participants |
| | Who Took |
| | Pre Quiz | Pre Quiz | Pre Quiz | Post Quiz | Post Quiz | Post Quiz |
| Lecture 1 | 12 | 18 | 30 | 11 | 17 | 28 |
| Lecture 2 | 14 | 18 | 32 | 14 | 18 | 32 |
| Lecture 3 | 12 | 18 | 30 | 12 | 16 | 28 |
| Lecture 4 | 11 | 16 | 27 | 7 | 14 | 21 |
| Lecture 5 | 12 | 14 | 26 | 8 | 12 | 20 |
| Lecture 6 | 10 | 15 | 25 | 6 | 13 | 19 |
| Lecture 7 | 6 | 15 | 21 | 3 | 13 | 16 |

Table 2: Participation by Lecture

3.4.2 Pre and Post-Lecture Quizzes

In order to analyze the knowledge-based data generated by the pre and post-lecture quizzes, the individual scores for each lecture were compiled and averages taken Table 3. The data from the Fall 2016 class and Spring 2017 class were analyzed together.

| | Average Pre- Lecture Score | Average Post- Lecture Score | Increase in Score |
|-----------|-------------------------------|--------------------------------|----------------------|
| Lecture 1 | 3.107 | 3.750 | 0.643 |
| Lecture 2 | 2.969 | 4.438 | 1.469 |
| Lecture 3 | 3.821 | 4.689 | 0.857 |
| Lecture 4 | 3.429 | 4.143 | 0.714 |
| Lecture 5 | 2.100 | 2.700 | 0.060 |
| Lecture 6 | 3.263 | 3.526 | 0.263 |
| Lecture 7 | 2.500 | 3.0625 | 0.563 |

 Table 3: Pre-Lecture vs. Post-Lecture Average Scores

A paired t-test was conducted for each of the seven lectures at the $\alpha = 0.05$ level of significance. Statistically significant increases in post-lecture scores were observed for Lectures 1-4, but not for Lectures 5-7. The results of the paired t-tests are shown in Table 4.

 Table 4: Results of Paired T-Test

| | Number of Observatio ns | Difference in Mean Score (Post – Pre) | Standard Error of Mean | Standard Deviation of Mean | 95% Confidence Interval of Mean | p-value | Statistical Significanc e at $\alpha =$ 0.05 |
|-----------|-------------------------------|--|------------------------------|----------------------------------|--|---------|---|
| Lecture 1 | 28 | 0.643 | 0.248 | 1.311 | 0.134- 1.151 | 0.0151 | Yes |
| Lecture 2 | 32 | 1.469 | 0.190 | 1.077 | 1.080- 1.857 | < 0.01 | Yes |
| Lecture 3 | 28 | 0.857 | 0.176 | 0.932 | 0.496- 1.218 | < 0.01 | Yes |
| Lecture 4 | 21 | 0.714 | 0.286 | 1.309 | 0.118- 1.310 | 0.0212 | Yes |
| Lecture 5 | 20 | 0.060 | 0.336 | 1.501 | -0.102- 1.302 | 0.0898 | No |
| Lecture 6 | 19 | 0.263 | 0.314 | 1.368 | -0.396- 0.922 | 0.413 | No |
| Lecture 7 | 16 | 0.563 | 0.387 | 1.548 | -0.262- 1.387 | 0.167 | No |

In addition to the overall pre and post-lecture quiz scores, two additional analyses were performed in order to determine if there were any significant differences in quiz scores between participant subgroups. After testing for equality of variance, two sample t-tests were run for each lecture for 1st year versus 2nd year students and for students with laboratory experience versus students without laboratory experience. The only statistically significant result that was found at the $\alpha = 0.05$ level of significance was that 1st year students had a greater increase in knowledge for Lecture 2 as compared to the 2nd year students.

3.4.3 Post-Lecture Satisfaction Surveys

In order to analyze the post-lecture satisfaction data, a number score was applied to the Likert scale from the post-series satisfaction survey, where a one corresponds to the most negative reaction, and the scores increase with a five corresponding to the most positive reaction. The average student rating of the importance of each lecture topic to their genetic counseling training is shown in Table 5.

The questions "*Please rate the quality of the speaker*" and "*Please rate the quality with which the information was presented*" have not been included in this table, as the lecturers may not have been the same between the Fall 2016 and Spring 2017 course offerings. The average ratings for these two questions were calculated for each course offering separately and reported back to course coordinator at GeneDx to be shared with the individual lecturers. All students who took the post-lecture quiz also provided answers to the post-lecture Likert scale questions, and these numbers can be found in Table 2.

| Question | Lecture 1 | Lecture 2 | Lecture 3 | Lecture 4 | Lecture 5 | Lecture 6 | Lecture 7 |
|--|--------------|-----------|-----------|--------------|--------------|--------------|--------------|
| Please rate the overall value of this lecture topic to your training | 3.75 | 4.41 | 3.96 | 4.43 | 4.37 | 4.42 | 4.27 |

Table 5: Student Rated Importance of Each Lecture

In addition to the Likert scale questions, a number of open-ended questions were asked of the students to determine what content they thought should be added to or removed from each lecture. Some example responses for each lecture can be found in Table 6.

| Lecture | Topics to hear more of | Topics to hear less of |
|--|---|---|
| 1 – The Role of a Genetic Counselor at GeneDx | "Level of experience, competency, and education of genetic counseling employees before beginning as a counselor at GeneDx." | "Working at home, it's cool but didn't need to spend so much time on it." |
| 2 – Things to Consider When Ordering a Test | "More of the case walk through and picking the types of technology for testing." | "Less of an overview needed on how the technologies work." |
| 3 – Application of Psychosocial Issues in the Lab | "More psychosocial cases would be helpful." | "The structure of GeneDx." |
| 4 – Tools Used in Variant Interpretation | "More interactive practice." | "Different types of variants." |

 Table 6: Example Student Reponses from Post-Lecture Satisfaction Surveys

| T | able | 6 | (Continu | ued) |
|---|------|---|----------|------|
|---|------|---|----------|------|

| 5 – Variant Interpretation Part II & Anatomy of a Report | "More controversial examples of variants that are classified, like where there can be some dispute about how to classify the variant or why a lab may choose one final decision over the other." | "I would have liked to spend less time going over the homework and more on the actual lecture." |
|---|---|--|
| 6 – Whole Exome Sequencing, Secondary and Incidental Findings | "More cases!" | "Could be more specific for second-years in rotations who already have basic WES information." |
| 7 – Incidental and Unique Findings | "More discussion about the cases, I felt like [they] were gone through pretty quickly." | "Have more interactions with the group. Maybe provide some homework the week prior to allow the students to be more engaged with the lecture." |

3.4.4 Post-Series Satisfaction Surveys

In order to analyze the post-series satisfaction data, a number score was applied to the Likert scale from the post-series satisfaction survey, where a one corresponds to the most negative reaction, and the scores increase with a five corresponding to the most positive reaction. Of the 36 students in the series, 17 (47.2%) completed the post-series satisfaction survey. Data from the post satisfaction survey is described in Tables 7, 8, and 9.

Overall, 17 students provided responses to the post-series satisfaction survey and most expressed positive or very positive reactions to the series. The two lowest scoring questions were "*Communicating with my classmates and instructors in this learning format was as good as in a traditional classroom*" and "*I feel that this learning experience provided me with knowledge that I had not yet received as part of my genetic counseling education*".

Table 7: Student Post-Series Satisfaction Data

| | Very negative – Negative (Score 1-2) (n, %) | Neutral (Score 3) (n, %) | Positive – Very Positive (Score 4-5) (n, %) | Mean Score |
|---------------------------|--|--------------------------------|--|------------|
| I would recommend | | | | |
| this learning | | | | |
| experience to other | 0 (0%) | 1 (6%) | 16 (94%) | 4.71 |
| genetic counseling | | | | |
| students. | | | | |
| It was as easy to learn | | | | |
| in this format as in a | 0 (0%) | 1 (6%) | 16 (94%) | 4.47 |
| traditional (i.e. in- | | - (0,0) | | |
| person) classroom. | | | | |
| I felt that this learning | | | | |
| experience was as | 0 (00() | 1 (60/) | 16 (0.40()) | 4.50 |
| comfortable as in a | 0(0%) | 1 (6%) | 16 (94%) | 4.53 |
| traditional (i.e. in- | | | | |
| person) classroom. | | | | |
| I felt that the | | | | |
| instructors were | O(O0/) | 1(60/) | $1 \in (0.40/)$ | 170 |
| invested in my | 0(0%) | 1 (6%) | 16 (94%) | 4.76 |
| success in this | | | | |
| Communicating with | | | | |
| Communicating with | | | | |
| instructors in this | | | | |
| logrning format was | 3 (18%) | 4 (23%) | 10 (59%) | 3.65 |
| as good as in a | | | | |
| as good as III a | | | | |
| I fool that this | | | | |
| learning experience | | | | |
| was valuable to my | 0(0%) | 1 (6%) | 16 (94%) | 176 |
| genetic counseling | 0(0/0) | 1 (0/0) | 10 (7470) | 4.70 |
| education | | | | |
| I feel that this | | | | |
| learning experience | | | | |
| provided me with | | | | |
| knowledge that I had | 3 (18%) | 1 (6%) | 13 (76%) | 3 71 |
| not vet received as | 5 (10/0) | 1 (0/0) | 10 (10/0) | 0111 |
| part of my genetic | | | | |
| counseling education. | | | | |
| Were the expectations | | | | |
| of the course | | | | |
| reviewed with you in | 0 (0%) | 0 (0%) | 17 (100%) | 4.94 |
| a clear and concise | ` ' | × / | | |
| manner? | | | | |

A number of open-ended questions regarding the series overall were asked of the students. The themes identified from student responses and selected quotes from them are shown in Table 8.

| Questions | Answers |
|--|---|
| What do you believe are the strengths of this GeneDx webinar series? | |
| Theme: Information | Offering education on a subject that other genetic counseling student may not get exposure to. |
| Theme: Behind the Scenes | Well organized, covered a variety of important topics, provided insight and understanding of GeneDx process |
| Theme: Cases | We had already had some of these topics covered, but this course was extremely helpful to clarify and it was great to have specific examples to tie the concepts to. (Case studies were very useful). |
| Theme: Experts | It was nice to have teachers coming from a unique background of experience outside of the clinic |
| What do you believe are the limitations of this GeneDx webinar series? | |
| Theme: Webinar Format | Conference call style communication made it difficult to engage and communicate at some times |
| Theme: Technology Issues | I think the technological aspect needs to be worked on. Sound and video would cut out, and often we had to yell to be heard. Additionally, we probably did not need an entire class necessarily on home offices, etc. |
| Please share any other thoughts you may have about this learning | I only attended three sessions because of a class conflicts but I wish I got to see more! Great experience overall. |
| experience. | I am lucky that in my program we have access to a lot of lab experience and learning very early, so I would not say that this webinar offered very much that was brand new to me. However, it was a great refresher and I feel that this is extremely valuable to students who are not in a location where these opportunities are not possible. I loved this. I'm not able to do a lab rotation and felt this was the next |
| | best thing. Thank you! I really enjoyed having a lab perspective on all of these topics. It helps when comparing the clinical experience with the behind the |
| | scenes action at the labs. |

 Table 8: Themes and Example Student Quotes from the Post-Series Satisfaction Survey

| Would you like to have additional (you may select more than one answer): | Responses | Comments |
|---|-----------|--------------------|
| In class discussion | 2 | |
| In class activities | 7 | |
| Hands-on assignments | 5 | |
| Other (please specify): | 1 | Additional classes |

Table 9: Additional Course Features Desired by Students

Similar to the analysis for the student satisfaction data, the program director satisfaction data were given number scores that corresponded with their Likert scale responses. All five program directors who answered the post-series satisfaction survey expressed very positive responses to their students' participation in the webinar series, as shown in Table 10.

| | Very negative – Negative (Score 1-2) (n, %) | Neutral (Score 3) (n, %) | Positive – Very Positive (Score 4-5) (n, %) | Mean Score |
|---|--|--------------------------------|--|------------|
| I feel that this learning experience was valuable to the student of my genetic counseling program. | 0 (0%) | 0 (0%) | 5 (100%) | 5 |
| I would recommend that future students in my genetic counseling program participate in this learning experience. | 0 (0%) | 0 (0%) | 5 (100%) | 5 |

Table 10: Program Director Post-Series Satisfaction Data

One open-ended question was asked of the program directors. All of the comments from the program directors can be found in Table 11.

| Question | Answers |
|-------------------------------------|--|
| Please share any other thoughts you | I look forward to getting my students involved in the course. Thank |
| may have about this learning | you! |
| experience. | |
| | I thought that the webinar style course went well. There were some |
| | technical difficulties during some of the presentations, including |
| | lost connections, but I am not sure that anyone has any real control |
| | over that. I did like that the webinars were live, which encouraged |
| | some discussion and also probably helped with students actually |
| | reviewing the content. While having recorded webinars may be |
| | helpful for scheduling purposes, it may be easier for students to put |
| | this off if it is not a scheduled event. Overall, my students appeared |
| | to enjoy the content and find it helpful. From the webinars that I sat |
| | in on, I would agree that this is important information for students |
| | given the expanding roles of genetic counselors in the field. |
| | I felt this was a valuable learning experience and that having |
| | "experts" deliver this content was quite helpful. Programs struggle |
| | getting in all the necessary content so having access to educational |
| | resources like this is valuable. |

Table 11: Program Director Comments from Post-Series Satisfaction Survey

3.5 DISCUSSION

The purpose of this project was to evaluate the GeneDx webinar series to determine if it was an effective and satisfactory way of educating genetic counseling students about the laboratory applications of the genetic counseling profession. Because four of the seven lectures showed a statistically significant increase in score from pre to post-lecture, the webinar was partially successful in increasing student knowledge. Additionally, both students and program directors found this to be a satisfactory experience and almost all would recommend the webinar series to future genetic counseling students.

The development and evaluation of the GeneDx webinar series were important for two main reasons. First, because many genetic counseling students may not have access to a formal genetic laboratory rotation as part of their training, opportunities to gain laboratory-relevant experience may be limited. GeneDx is a widely known genetic laboratory and has trained genetic counseling students in the past, and as a result, they were well situated to develop this series and provide this learning opportunity, which can help students achieve the ACGC required laboratory experience. Second, online learning modules are being increasingly used for genetic counselors and genetic counseling students despite there being a lack of published literature regarding its effectiveness. Since GeneDx hopes to continue offering this webinar series in future, it was important to evaluate this series to ensure that it was effective in meeting its goals.

Although the results of this project are not generalizable outside of this specific series, they do provide support for the future development of the GeneDx webinar series and may offer insight for further research into the development and evaluation of online learning programs for genetic counseling students.

The GeneDx webinar series utilizes some aspects of the constructivist learning approach, including a user-focused design and content that is reflective of the students' future professional practice⁵⁵, so the results of this project were reassuring. For example, students particularly appreciated the relevance to their future practice as genetic counselors and enjoyed working through case examples as problem-solving exercises. Although there is not an in-person component, the current flexibility of the GeneDx course has a blended flavor since it allows students to converse via conference call with the instructors and classmates. Additionally, students in the same geographical area could convene together during the time the course is going on. The students at the University of Pittsburgh took advantage of this option and secured a room on campus each week so that they could attend the webinar as a group.

The results from two randomized control studies by Lovett et al. (2008) and Bowen et al. (2012) showed that students in blended course actually achieved similar results to their counterparts in a traditional course in less time.^{43,53} This result is promising for our project, as

one challenge currently experienced by genetic counseling programs is getting a growing body of information to students in an efficient manner.

3.5.1 Pre and Post-Lecture Quizzes

The main purpose of the webinar series was to educate genetic counseling students about the laboratory applications of genetic counseling, which appears to have been partially achieved based on the statistically significant increase in post-lecture quiz scores for Lectures 1-4. This indicates that student's knowledge likely increased as a result of each of these four lectures, and not simply by chance. This finding contributes some evidence in support of the effectiveness of online learning for genetic counseling students. There were no statistically significant increases in score for Lectures 5-7.

There are a number of variables that might have contributed to the smaller increase in post-lecture scores for Lectures 5-7. First, the content that was contained in these last three lectures was more advanced than that of the first four lectures. Therefore, students may have required more time and practice to feel comfortable with the material. Another consideration could be maturation bias. Since the webinar series took place over the course of at least eight weeks during times when students were actively taking classes, they may have learned the same material that was given in the webinar in another class, thereby reducing potential knowledge gains as the webinar series progressed.

Also of note, is a considerable attrition rate, which was observed particularly in the Fall 2016 offering of the course. The total number of students who took part in the series was 36, but only 16 students participated in the last lecture. The breakdown of students per lecture is documented in Table 2. The lack of participation, particularly later on in the series, may be one

explanation for the inability to determine statistically significant increases in scores for Lectures 5-7.

Although the reasons for the attrition rate were not formally investigated as part of this project, some speculations can be made about potential causes. First, one can imagine that as the semesters progressed and holidays and exams were approaching, that students may not have felt that this additional voluntary learning experience was a high priority and stopped attending the lectures. Another reason, as evidenced by the satisfaction surveys, could be that students had already had this information previously, and so it may not have felt worthwhile for them to continue with the series. It is also possible that students dropped out of the series because they did not like the format of the webinars. A number of comments on the satisfaction survey cited that a limitation of the series was technological issues. It would be beneficial to future offerings of the webinar series to investigate this issue in greater detail.

In order to combat the attrition rate that was observed in the Fall 2016 offering of the course, the webinar development team decided to take attendance during the Spring 2017 offering of the course. Prior to the start of the Spring 2017 series, the webinar development team asked that if students wanted to list this learning experience on their resumes that they participate in at least four of the eight webinars. Although no formal analysis was done, it appears that fewer students dropped out of the Spring 2017 series than the Fall 2016 series.

3.5.2 Post-Lecture Satisfaction Surveys

The purpose of the post-lecture satisfaction surveys was to provide feedback to GeneDx for future improvements in the webinar series with regard to speaker quality, clarity with which the information was presented, and importance of material to students' genetic counseling training.

When the data regarding the importance of each lecture were analyzed, all average lecture scores were greater than three (neutral on the Likert scale), indicating that students felt that every lecture was overall more important to their training than not. The lectures that students rated of the highest importance were Lecture 2 – Things to Consider When Ordering a Test (average score = 4.41), Lecture 4 – Tools Used in Variant Interpretation (average score = 4.43), and Lecture 6 – Whole Exome Sequencing, Secondary and Incidental Findings (average score = 4.42).

When students were asked what topics they would like to hear more of during the lectures, a general trend was that students would like to have more example cases to work through in detail as a group. When asked what they would like to hear less of, students responded that the lecturers did not need to spend so much time on foundational concepts like types of testing technologies and examples of genetic variants. These results suggest that students may have already received basic information about laboratory genetics either in their coursework or other experiences. The demographics collected at the start of each series show that 52.8% of students had previous work experience in a laboratory setting and 22.2% had a laboratory rotation as part of their genetic counseling training.

Two strengths of the webinar series, as described by multiple comments on the satisfaction surveys, were the expert lecturers and the opportunity to work through example cases. Therefore, it is likely that a greater benefit of the series is the ability to relate the material to real-life practice, rather than just accepting new information from lecturers. These results appear to be congruent with available literature on online learning in that students are overall more satisfied with engaging lectures that are relevant to their professional practice rather than those that simply transfer information from teacher to student.^{36,37,46,58}
These lectures can be revised in future offerings of the webinar series to incorporate the feedback from the open-ended questions so that they are even more valuable to students. This "bottom up" user-centered approach will likely improve student satisfaction with this learning experience.^{8,46,58}

3.5.3 Post-Series Satisfaction Surveys

One of the goals of this project was to evaluate participant satisfaction with this particular online learning experience. Although satisfaction does not necessarily reflect a change in knowledge⁸, it is still an important aspect of an educational program. Overall, students indicated a positive experience with the GeneDx webinar series and almost all (94%) felt positively about recommending this experience to other genetic counseling students.

A number of themes emerged when reviewing the open-ended responses. When asked about the strengths of the GeneDx webinar series, the following themes were identified: example cases, behind the scenes look at laboratory work, information contained in the series, and experts in the field. As was mentioned above, it appears that the students' greatest perceived strengths of the GeneDx series were the expert lecturers and example cases that were presented during the lecture.

Across all offerings of the course, the individual speakers quality ratings based on the five-point Likert scale were greater than four, indicating that most students felt that the speakers were "good" to "excellent". Additionally, multiple post-series comments specifically mentioned the value of having expert instructors with specialized experience in the field of laboratory genetic counseling. By offering personal or professional narratives in their lectures, instructors

can effectively contextualize the knowledge they are imparting to the students which is more engaging to students than simply disseminating facts.⁴⁶

Another strength of the series based on the satisfaction survey results was the benefit of the example cases and scenarios during lectures. Students seemed to appreciate the insight into the real-world application of the information that they had learned. As demonstrated in the literature, the relevance of learned information to future professional practice is important in creating an effective and satisfying learning experience.^{36,37,46,75}. Students are more likely to be invested in a course and enjoy learning the material when it is related to their future professional practice.⁴⁶

When asked about the limitations of the GeneDx webinar series, the following themes were identified: technological issues, challenges with the webinar format (communication), and redundant information. Issues with technology have been cited in the past as a challenge of online learning experiences³⁷, but this seems to mostly relate to a users' comfort in using web-based technology. Because of the widespread use of computers and the internet in present-day academia, it is unlikely that the students of the GeneDx webinar series were uncomfortable with their use. Though most of the student comments regarding technological issues were very general (e.g. "Adobe Connect does not lend itself to interactivity."), they seemed to refer to challenges that may have occurred as a result of the software selected for the series, such as a possible lag between audio and video (e.g. "Sound and video would cut out..."). The webinar team should investigate these issues for future offerings of the GeneDx course. If improvements are too difficult or costly to make, perhaps another webinar software should be considered.

The survey question with the least positive response was regarding the ease of communication with other students and course instructors. While the majority (59%) of respondents had overall positive feelings about this aspect of the webinar series, another 41%

reported neutral or negative feelings. This is not necessarily surprising, as the literature suggests that communication is a challenging part of distance learning due to the more isolated nature of learning outside of a traditional classroom.^{37,75} Although online modalities do offer means of communication such as email, instant messaging, and discussion boards, the learning atmosphere is different than the traditional in-person learning environment that most students are used to.⁴⁶ To be successful, students and instructors must be willing to adapt their methods of communication to the online platform.

Interestingly, one student commented that a limitation of the course was "Not being able to see others. I think this hindered discussion [because] you never knew if someone was going to talk or if you should." At the start of each lecture for both the Fall 2016 and Spring 2017 courses, the instructors welcomed students to share their own webcams in order to see one another. Aside from the University of Pittsburgh group who all joined the webinars from one room with a webcam, no other students elected to share their own video feeds. It would be interesting in future offerings of the series to see if by making video sharing a requirement, students report better communication.

One unexpected, but reassuring finding from the post-series satisfaction survey was that students reported that they had already received the information contained in the webinar series as part of their genetic counseling training. This indicates that program directors have already made headway in incorporating new and specific knowledge regarding the laboratory applications of genetic counseling for the students of their programs. In the open-ended responses, three comments addressed this issue specifically. Two of the three comments mentioned that although some of the course content was not new to them, it was helpful to have a refresher and specific case examples to work through. The third comment stated that since some programs are already covering this information, the course could be redundant for some students. Additional evaluation of the effectiveness of the GeneDx webinar series for specific sub-groups of students could help to identify which students would most benefit from the experience.

3.5.4 Limitations of the Project

While the results of the project demonstrated an increase in student knowledge and students as well as program directors indicated satisfaction with the series, there are some limitations. First, not all students participated in all webinars, and even fewer completed the post-lecture knowledge/satisfaction and post-series satisfaction surveys. It could be possible that there is a skewed response in which students with particularly positive or negative feelings about the experience were likely to provide feedback, whereas students who felt more neutrally may not have felt inclined to make comments.

We did not compare this webinar series with the same (or similar) course taught inperson. Because there was no alternative available, participants may have provided what Woods et al. (2009) referred to as "obliged endorsements⁷⁶, meaning that they provided positive feedback simply because any opportunity would be better than no opportunity. Since many students had not focused on laboratory applications during their clinical rotations, their reported satisfaction with the GeneDx webinar series may have actually been a "better than nothing" reflection of a perceived benefit of having this opportunity rather than true satisfaction with this particular learning experience.

One significant limitation of this project is that the post-lecture quizzes were given immediately after each lecture. Given this structure, it is likely that the quizzes are measuring information recall and not necessarily competence. It would be more informative to try to ascertain retention of information by giving post-lecture quizzes a month or more after the conclusion of the series, as was done in the 2005 study by Fordis et al.⁵¹. By following up with physician participants immediately after and subsequently 12 weeks after an online CME course, the authors were able to conclude that participants had both recalled and retained the information that they learned and were in fact using in their practice.⁵¹. In fact, the scores on the quizzes given 12 weeks after the course were higher than both the pre-course quiz and the quiz given immediately post-course.⁵¹

As a convenience for students, lecture notes were emailed out at the start of each lecture. Rather than relying on their knowledge alone, students could have reviewed the material prior to the post-lecture quiz or while they took it. Because students took the quizzes from their own personal computers, often in their own homes, there was no way for instructors to ensure that students were not using notes or other outside resources for aid. It is therefore possible that pre and post-lecture scores may be inflated. On the other hand, since this experience was relatively anonymous and the students' scores were not reported back to their learning institutions, students may have actually been less inclined to use outside resources.

Since this webinar series was optional and no formal incentives were provided to encourage participation, the results could be inherently biased based on the population of students who elected to participate. Of the 19 students who were reported to have had laboratory experience prior to beginning their genetic counseling program, 17 described themselves as "interested" or "very interested" in working in a laboratory setting after the completion of their degree. It is possible that these characteristics may have impacted the data that were collected. For example, students with prior laboratory experience may have already had exposure to some of the material contained in the lectures and therefore may not have had as great an increase in post-lecture score as a student learning that information for the first time. Or, those interested in working in a laboratory as a genetic counselor could have been more motivated to pay careful attention during lectures and provide positive feedback about the importance of the topics.

Important to note is that although no formal incentives were used to encourage students to join the webinar series, it is possible that an internal bias in the project may have influenced participation. The participating learning institutions were a convenience sample selected based on relationships with the webinar team or previous contact with GeneDx to facilitate learning opportunities. For example, the primary author is a student at the University of Pittsburgh, and fellow classmates may have felt compelled on a personal level to participate.

3.5.5 Future Work

An important next step in evaluating the effectiveness of the GeneDx webinar series is to followup with students to assess their information retention over time. True learning is not just the acquisition of new knowledge, but rather is the ability to produce results.⁷⁷ If it can be shown that students who participated in the series are able to recall and use the information that they acquired, then it would be reasonable to conclude that they indeed learned from the experience. Both short term (within months) and long term (within years) follow up should be considered.

Though it might be difficult to do, ascertainment of the impact of this specific webinar series to one's future genetic counseling practice would be ideal. For example, it would be useful to determine if the GeneDx webinar series provided participating students with knowledge or skills that did not overlap with other aspects of their training. Follow up with students after they have been working for some years would be necessary in gathering this information.

Appreciating the learner and his/her experience is helpful in building an effective course.^{7,37} Based on feedback from the two course offerings, GeneDx may consider adding

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additional hands-on learning assignments as well as more case studies, which many students indicated were useful. The addition of such examples and assignments will likely be of use in reinforcing the material contained in the lectures, particularly for the lectures with no statistically significant increases in knowledge (Lectures 5-7). It is reasonable to consider that more practice with new or difficult concepts like variant interpretation is likely to result in increased scores.

Additionally, if this course is to be offered in the future, then it is important to evaluate the program periodically to ensure that it is still meeting its goals. Genetic technologies evolve rapidly, so keeping the GeneDx webinar series up to date will be key in its benefit to genetic counseling students.

With more data, it may also be useful to further evaluate the data generated and measure outcomes based on specific subgroups of students. In doing so, it might be possible to tailor this learning experience and recommend it to more specific subgroups of genetic counseling students, based on who would benefit from it the most. In an attempt to answer these questions, two subgroup analyses were run: 1) 1^{st} versus 2^{nd} year students and 2) students with laboratory experience versus students without laboratory experience. The only statistically significant result that was found at the $\alpha = 0.05$ level of significance was that 1^{st} year students had a great increase in knowledge for Lecture 2 as compared to the 2^{nd} year students. After modifying the webinar series based on the feedback from the Fall 2016 and Spring 2017 courses and gathering additional data, it would be helpful to revisit these subgroup analyses in future.

Another further avenue for future work on this series would be to compare it to the same (or similar) course taught in person. Even though there is evidence in the literature to support that online learning can be just as effective as in-person learning^{6,7,39,43}, no studies have been done to date for genetic counseling students. If this series could be evaluated alongside an in-person course and produce similar outcomes, it would strengthen the conclusion that the GeneDx

webinar series is an effective way to educate genetic counseling students about the laboratory applications of the profession.

3.6 CONCLUSIONS

In conclusion, the GeneDx webinar series was shown to be relatively effective in increasing genetic counseling students' knowledge about some applications of laboratory genetic counseling from pre-lecture to post-lecture. The three lectures for which statistically significant increases in knowledge were not observed arguably contain newer and more difficult material, therefore the students' suggestions to add additional case examples and in-class activates may be useful in changing this outcome in future. Overall, students and program directors found this educational experience to be satisfying and would recommend that it be offered to other genetic counseling students.

Though these results are not generalizable to a wide population, the partial success of this project, along with literature documenting the effectiveness of online learning for medical professionals^{49,51,64}, provides evidence in support of the use of online learning for genetic counseling students. With additional modifications and further evaluation, the GeneDx webinar series may prove to be a reasonable alternative to in-person learning in an effort for genetic counseling students to gain ACGC required laboratory experience.

4.0 SIGNIFICANCE TO GENETIC COUNSELING AND PUBLIC HEALTH

4.1 SIGNIFICANCE TO GENETIC COUNSELING

The evaluation of the GeneDx webinar series as an educational tool is significant to the field of genetic counseling. It addresses the ACGC's curriculum Standard to educate students about the laboratory applications of genetic counseling³, making this a valuable experience for the genetic counseling students and program directors from the five ACGC accredited programs that participated in the series. This Standard is of particular importance as a growing number of genetic counselors are specializing in laboratory work.⁴

This project will contribute to the literature as an evaluation of a genetic counselorspecific training series. Though the results of this study do not provide generalizable information beyond this specific webinar series, they do provide evidence in support of the use of online learning for genetic counseling students and may offer insight for others considering future online education opportunities.

Despite the success of this project and the evidence supporting the effectiveness of online learning in other health professions^{37,49,64}, it is unlikely that online learning will completely replace traditional genetic counseling training. There are a number of aspects that require inperson learning and hands-on training, most notably, the clinical experience. However, there is evidence to support that online learning, particularly for students of the health sciences, may be more effective if blended with traditional learning.⁴⁸ Therefore, a reasonable use of online

education for genetic counseling students could be used to keep up with the ever-growing body of knowledge as the field develops. In the future, online learning could allow genetic counseling programs to become more flexible with their coursework and perhaps facilitate a more gradual introduction to the field of genetic counseling by allowing students to begin their training or complete some basic requirements at a part-time pace.

In fact, two genetic counseling programs have already employed the use of online learning in their curriculum. The University of Arkansas for Medical Sciences (UAMS) offers a master's program in genetic counseling in which most of the coursework is blended with both live instruction and online components.⁶¹ The UAMS program also provides the opportunity for students to take their clinical rotations at off campus sites due to the ability to attend classes via interactive video conferencing.⁶¹ The Bay Path University master's in genetic counseling program, set to launch their first class in the fall of 2017, advertises their coursework as flexible and blended, by offering classes online and on-campus on the weekends.⁶²

In addition to the relevance of this project to the genetic counseling students and program directors who participated in this learning experience, this project also required the use of a number of core genetic counseling skills on the part of the group that designed, launched, and evaluated the webinar series.

First, by designing the webinar lectures, writing knowledge-based quiz questions, and successfully instructing students, the group demonstrated knowledge and understanding of genetics. Several lecturers provided the students with a number of real-world cases as means of explaining appropriate genetic testing strategies. Additionally, in order to gather evidence in support of the webinar series, the group critically assessed the available literature regarding online learning, particularly with regard to genetic counselors and other health professionals.

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These activities fall under the ACGC's "Genetics Expertise and Analysis" Practice-Based Competency.⁷⁸

Based on the statistically significant increases in post-lecture knowledge and the overall satisfaction on the part of the students and program directors, it is evident that the group effectively gave presentations on subjects that were relevant to the target audience. Using the feedback that was received throughout the course of this project, the group will continue to further develop the webinar series in order to better facilitate the needs of genetic counseling students. These activities fall under the ACGC's "Education" Practice-Based Competency.⁷⁸

4.2 SIGNIFICANCE TO PUBLIC HEALTH

This project is of particular public health significance due to the increasing demand for and availability of genetic testing, which is often facilitated by a genetic counselor. In a 2016 poll conducted by STAT and Harvard T.H. Chan School of Public Health, it was found that 6% of randomly sampled Americans have already undergone genetic testing for a number of reasons, suggesting that genetic testing is becoming more commonplace.⁹ In this same survey, a subset of respondents were asked about their desire to have predictive genetic tests for diseases like Alzheimer's and cancer, and more than 50% of people said that they would want to have such testing if it were available to them.⁹ Another survey conducted in 2016 among individuals participating in Amazon Mechanical Turks indicated that a majority of individuals (64.92%) would take a genetic test immediately to learn more about their hereditary predisposition to cancer, and another 26.84% would consider doing so sometime in the future.¹⁰

These surveys highlight the importance of educating genetic counseling students about the laboratory applications of the profession to ensure that they are prepared to enter the workforce with functional knowledge of genetic testing options. In the future, genetic testing will become even more integrated into many aspects of medicine such as clinical care, direct-toconsumer testing, personalized medicine, and population screening programs, and it is therefore essential that genetics education follows this growth.⁸ Effective and satisfactory educational resources, such as the GeneDx webinar series, aid genetic counseling programs in providing students with this important laboratory experience, thereby increasing the capacity to provide services to the growing number of patients undergoing genetic testing.

The Core Competencies for Public Health Professionals are the foundational skills that professionals should be able to demonstrate in the practice, education, and research of public health⁷⁹. A number of these skills were utilized in the execution of this project:

- Analytical/Assessment Skills The group used analytical and assessment skills by evaluating the current literature regarding online learning and recognizing a need in the genetic counseling community for additional educational opportunities for students.
- Policy Development/Program-Planning Skills The group used program-planning skills by creating an online webinar series that highlighted the important topics related to laboratory genetic counseling. By implementing satisfaction surveys in the webinar series, the group assessed the program to ensure that it meets the needs of the students who participated.
- Communication Skills The group utilized communication skills in order to facilitate the webinar series for students across geographical constraints. The use of different technologies was carefully considered when deciding on a medium in which to host the

series, as to best foster discussion and learning. Based on student feedback, this aspect of the webinar series was challenging, and requires some additional troubleshooting.

- Public Health Sciences Skills In order to gather evidence in support of this project, the group critically assessed the available literature. Additionally, the data gathered from this project will help to further develop future offerings of the webinar series. These activities demonstrate the group's ability to assess and synthesize evidence to contribute to public health science.
- Leadership and Systems Thinking Skills The group utilized leadership and systems thinking skills by reflecting on the needs of the genetic counseling community and teaching and mentoring students, resulting in increased knowledge regarding the laboratory applications of genetic counseling.

The 10 Essential Public Health Services are activities that are related to the three core functions of public health: assessment, policy development, and assurance.⁸⁰ The development of the GeneDx webinar series provided the following public health services:

- Mobilize Community Partnerships and Action to Identify and Solve Health Problems After identifying a need in the genetic counseling community, GeneDx developed a carefully structured webinar series to educate students about the laboratory applications of genetic counseling. GeneDx then successfully collaborated with the University of Pittsburgh to launch this webinar series and evaluate its effectiveness in meeting its goals.
- Assure Competent Public and Personal Health Care Workforce In offering the GeneDx webinar series to genetic counseling students, the webinar development group helped genetic counseling training programs to meet one of the ACGC Accreditation Standards for laboratory experience³. These Standards protect the public and the integrity of the genetic counseling profession by ensuring a competent workforce³.

 Research For New Insights and Innovative Solutions to Health Problems – GeneDx has been involved in the training of genetic counseling students in the past, but the webinar development group exercised innovation in creating this webinar series to keep pace with the growing demand for student rotations in a laboratory setting. In doing so, they provided an educational opportunity for many more students than would have otherwise been possible.

5.0 PUBLIC HEALTH ESSAY

5.1 BACKGROUND

5.1.1 Introduction

Since the implementation of the Human Genome Project, there has been a rapid growth in genetic technology, which is changing the way that the world thinks about genetics and healthcare. Current genetic testing initiatives are driving the demand for these services on the part of healthcare providers and patients alike, thereby increasing the need for more trained genetics professionals who can appropriately interpret the results.

In 2015 former President Barack Obama launched the Precision Medicine Initiative (PMI), a patient-powered research effort intended to accelerate biomedical research in order to improve health and treat disease.⁸¹ In the past, most medical treatments were designed to treat the "average patient", resulting in successful treatments for some patients, but not for others. Through the PMI, clinicians would be better equipped with new knowledge and tools, thereby being better able to predict which treatment might be most effective for a particular patient.⁸¹

The United States is not the only country pushing toward precision medicine. In 2012, a company called Genomics England, which is owned by the United Kingdom Department of Health, launched the 100,000 Genomes Project, with the goal of sequencing the genomes of British citizens with cancer, rare diseases, and their family members.^{82,83} Two main goals of the

100,000 Genomes Project are to create a genomic medicine service for the United Kingdom's National Health Service (NHS) and to enable new medical research.⁸³

In addition to the formal population-based initiatives that have been developed, there are also now a number of direct-to-consumer (DTC) genetic tests on the market for a variety of purposes including ancestry and family history as well as testing for increased risk of certain diseases.⁸⁴ These DTC tests, which are well advertised on television and the internet, are increasing in popularity. 23andMe, which is only one of the many DTC companies currently in the marketplace, has more than doubled their customer base since 2015, from 800,000 to more than 2 million kits ordered.⁸⁵

A number of surveys that have been done indicate that the general population interest in genetic testing far outweighs even the robust customer bases of companies like 23andMe. In a 2016 poll conducted by STAT and Harvard T.H. Chan School of Public Health, it was found that 6% of randomly sampled Americans have already undergone genetic testing for a number of reasons, suggesting that genetic testing is becoming more commonplace.⁹ In this same survey, a subset of respondents were asked about their desire to have predictive genetic tests for diseases like Alzheimer's and cancer, and more than 50% of people said that they would want to have such testing if it were available to them.⁹ Another survey conducted in 2016 among individuals participating in Amazon Mechanical Turks indicated that a majority of individuals (64.92%) would take a genetic test immediately to learn more about their hereditary predisposition to cancer, and another 26.84% would consider doing so sometime in the future.¹⁰

In time, it is anticipated that genetic tests will continue to grow in complexity. As precision medicine is further integrated into daily practice, the expectation is that more information will be coming from genetic tests, and successful integration depends in part on the correct clinical interpretation of results.⁸⁴ Increasingly, physicians are being called upon to

interpret genetic tests, and many physicians feel ill-prepared to interpret these results.⁸⁴ A 2011 survey of 382 primary care physicians and internists in North Carolina revealed that although a majority of physicians felt that DTC genetic testing could be clinically useful, only 15% felt comfortable answering patient questions about DTC genetic tests and their results.⁸⁶ This suggests the need for a comprehensive physician education program about the benefits, limitations, and utility of genetic testing.⁸⁶

Because most healthcare providers are insufficiently trained to interpret genetic information⁸⁷ and many do not feel comfortable in doing so, the American College of Medical Genetics and Genomics recommends the involvement of a genetics expert when patients who have undergone genetic testing request consultations.⁸⁸ Since many different types of genetic testing are available to patients, it is important that healthcare providers have at least enough knowledge to know when to refer someone who has questions about genetic testing to a specialist.

An issue of critical importance is that although there are professionals such as geneticists and genetic counselors who have specialized training in interpreting genetic test results, the current and future demand for their services is higher than the number of such professionals that currently work in the field.⁸⁴ According to a 2014 statistic from the American Board of Medical Genetics and Genomics, certified clinical geneticists account for only 0.18% of all practicing physicians in the United States, and many of the positions in the training programs for geneticists are going unfilled.⁸⁴ For genetic counselors, the supply is not expected to reach equilibrium with the demand for services until at least the year 2023.⁸⁹

Though there may be some overlap in responsibilities, there is a significant distinction between clinical geneticists and genetic counselors. Clinical geneticists are physicians who are generally responsible for the diagnosis and management of patients who have a genetic disease.⁹⁰

Genetic counselors are more focused on the impact of genetic disease on a patient and their family, and help them adapt to the subsequent burdens of that disease.⁹⁰ Putting genetic information into a personal context is a particularly valuable aspect of genetic counseling to patients.⁹¹

To gather information on the patient perspective of the impact of genetic counseling, Veach et al. (1999) conducted interviews with 28 former genetic counseling clients that were seen at a major Midwestern university.⁹² They were asked questions that included how helpful they found the session, and their willingness to return to genetic counseling.⁹² Most patients (93%) felt that their genetic counselor was helpful and 75% were willing to return to see a genetic counselor in the future.⁹² Patients also found their counselors to be nondirective, nonjudgmental, and supportive.⁹²

In a similar study by Berhardt et al. (2000), 19 clients of seven experienced genetic counselors in the Baltimore-Washington, D.C. area participated in semi-structured phone interviews to share their thoughts their past genetic counseling experiences.⁹¹ The results showed that patients were appreciative of the amount of time that their genetic counselor spent with them and felt that the information was provided to them in a clear, comprehensive, and unhurried manner.⁹¹ In addition, thirteen out of nineteen patients who were interviewed said that they did not think that another healthcare provider could have provided the same service to them.⁹¹ These studies, which were conducted across multiple genetic specialties, highlight the role of a genetic counselor as an expert healthcare provider.

The current landscape of healthcare is changing, and an increasing number of patients and physicians are being exposed to genetic testing in various forms. Having a specialized and adequately trained workforce is important in realizing the benefits of genetic technologies and protecting patients and consumers from harm.⁹³ The need for more genetics health professionals

has been recognized, but a number of barriers exist in adding more experts to the workforce. Unlike geneticists, whose training programs have an excess of positions available and a shortage of interest⁸⁴, genetic counseling training programs have an abundance of interest, but end up turning away hundreds of qualified candidates each year.⁸⁹ As such, there are a number of challenges in the workforce and training programs that must be addressed in order to get more qualified genetic counselors practicing in the field.

5.1.2 Genetic Counseling Workforce Issues

Genetic counselors play a unique role in the ordering, reporting, and interpretation of genetic tests. Due to the advances in genetic technology, genetic counselors now have many new professional opportunities and the United States Department of Labor Bureau of Labor Statistics projects a 29% growth rate for genetic counseling jobs between 2014 and 2024¹, as compared to the 7% average increase across all other professions.² Though the growth of the profession is promising, it brings along a number of challenges.

There is a now an incongruence between the rapid growth of genetic technology and the size of the medical genetics workforce.⁹⁴ In order to better understand the supply and demand of United States-based genetic counselors, the Genetic Counselor Workforce Working Group (a collaboration between the American Board of Genetic Counseling, the Accreditation Council for Genetic Counseling, the Association of Genetic Counseling Program Directors, the American Society of Human Genetics, and the National Society of Genetic Counselors) commissioned a workforce study to be done.⁸⁹ The results of this study show that the genetic counseling workforce has grown by 88% from 2006-2016 and is projected to grow an additional 72% by 2026.⁸⁹

It was also found that there is a shortage of genetic counselors who participate directly in patient care, which indicates a demand for such services.⁸⁹ The supply of genetic counselors should be expected to reach equilibrium in 2023 or 2024, assuming the demand for a genetic counselor is one per 100,000 people in the United States⁸⁹, and that genetic counseling programs continue to grow at the same rate of approximately 5%. Additional research is planned to assess whether one genetic counselor per 100,000 or 75,000 is a more appropriate figure considering the demand in the clinical setting.⁸⁹

Contributing to the shortage of clinical genetic counselors is the increasing number of individuals who are choosing to work in nonclinical roles. Of the genetic counselors who responded to the NSGC's 2016 Professional Status Survey, 23% reported working in a position in which they do not counsel patients⁵, up from 18% of counselors who responded to the previous Professional Status Survey in 2014.⁷⁴ These counselors generally have a higher income and greater opportunities for professional growth⁵, which may explain why many genetic counselors are leaving their clinical roles to pursue work in a nonclinical setting. There are many shared skills between clinical and laboratory-based genetic counselors (LBGC's), which makes it reasonable for genetic counselors to transition between the two roles.

LBGC's have a unique and important role in the field of genetic counseling, and that role continues to expand with the growth of genetic technology. Most of a LBGC's time is spent liaising with customers, coordinating patient cases, and interpreting and reporting genetic test results.⁴ Other responsibilities include sales and marketing, counseling patients, research, management, test development and performance, website and database support, education and supervision of students, and insurance and billing.⁴ It is important that these roles be filled, especially given the growth of genetic technology, but care needs to be taken to balance the number of counselors in these roles with clinical genetic counselors as to not create further gaps

in the workforce. The Genetic Counselor Workforce Group is planning research to identify the actual demand for genetic counseling services outside of the clinical setting to better understand this issue.⁸⁹

Genetic counseling workforce issues are not unique to North America and are encountered in other parts of the world as well. A 2011 survey to obtain baseline data about the number and type of genetics professionals in 18 European countries determined that there were 494 genetic counselors and 122 genetic nurses for a population of around 319 million people; the equivalent of one genetic counselor or genetic nurse per 500,000 individuals.⁹⁵ It would appear that Europe has an even greater workforce gap than North America, however, there are differences among the various healthcare systems and roles of healthcare providers that may make direct comparisons difficult.⁹⁵ Of note, in 2011, the recognition of genetic counseling as its own unique profession was still up for debate in many European countries, and the lack of accreditation systems made it possible for anyone to assume the title of "genetic counselor", regardless of educational background or formal training.⁹⁵

Despite the increased demand for genetic counselors, the number of newly trained professionals who enter the workforce each year has remained relatively stable, thereby increasing the workforce gap. For example, approximately 300 students graduated from North American genetic counseling programs in 2016, filling less than half the estimated 650 job openings around that time.⁹⁶

A 2016 survey of genetic counseling program directors revealed most program directors felt that programs should actively be increasing the number of graduates each year.⁸⁷ On average, programs can accommodate a maximum of eight students per class, with a range of four to 25 students.⁸⁷ Unfortunately, the current demand for placements in training programs cannot currently be met given the resources of the available genetic counseling programs. Each year,

only about 30% of applicants are accepted²⁴ and hundreds of qualified applicants are turned away.⁸⁹

According to a survey by Pan et al. (2016), many genetic counseling program directors feel that one of the greatest barriers to increasing the size of programs is the availability of clinical training sites, which is impacted by many factors.⁸⁷ For example clinical centers that have the personnel to train genetic counseling students are geographically sparse, and because there is an existing shortage of clinical genetic counselors⁸⁹, many sites are already saturated with students.⁸⁷ Therefore, it would be difficult to increase the number of students at existing training sites without reducing the number and variety of patient cases.⁸⁷ In order to increase the capacity of genetic counseling training programs, it is important to investigate alternative avenues for students to gain clinical experience.

In the future, genetics will become even more integrated into many aspects of medicine such as direct-to-consumer testing, personalized medicine, and population screening programs, and it is therefore essential that genetics education follows this growth⁸ to ensure a properly trained workforce that will care for the increasing number of patients seeking out genetics services. Rather than trying to place more students into training sites that are already at capacity, a possible solution could be for genetic counseling programs to allow their students to train at sites that may not be geographically near their learning institution. A few genetic counseling programs in the US and UK have made just such an accommodation by giving their students the opportunity to take many of their classes online.^{61,62,97}

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5.1.3 US Genetic Counselor Training

The specialized education and training for genetic counselors began in 1969 with the formation of the first training program, and there are currently over 40 accredited genetic counseling programs in the United States and in Canada.^{22,23} These programs differ with regard to the specific coursework and clinical experiences offered, but to be accredited by the Accreditation Council for Genetic Counseling (ACGC) programs must meet certain standards.²⁴

Accredited genetic counseling programs are required to be, at minimum, 21 months or two academic years in length.³ According to the ACGC's Standards of Accreditation for Graduate Programs in Genetic Counseling (2013), programs' curriculum should include, but not be limited to, the following content areas: principles of human genetics, applicability of related sciences to medical genetics/genomics, principles and practice of clinical/medical genetics, psychosocial content, social, ethical and legal issues in genetics, health care delivery systems and principles of public health, education, research methods, and professional development/self-care. Additionally, students are required to have clinical and laboratory experiences and participate in a minimum of 50 "core cases", which develop the fundamental clinical counseling roles.³ By graduating from an ACGC accredited program, students demonstrate their mastery of a standardized curriculum relevant to the genetic counseling profession.³

In addition to preparing genetic counseling students for future practice, US genetic counseling programs are also actively addressing two significant workforce issues. First, genetic counseling programs are growing in size and number across the country in order to increase the number of qualified graduates into the profession. Second, additional emphasis is being placed on training for students in nonclinical roles in an effort to provide students with experience that will be most relevant to them in the current climate of the profession.

In an effort to expand the educational opportunities available to students, two US genetic counseling programs have employed the use of online learning in their curriculum. Although there is no genetic counseling specific literature regarding its use, it has been demonstrated to be effective for other medical professionals^{49,51,64} and has been endorsed by the National Society of Genetic Counselors as means for practitioners to continue their professional education.⁶⁰

The University of Arkansas for Medical Sciences (UAMS) offers a master's program in genetic counseling in which most of the coursework is blended with both live instruction and online components.⁶¹ The UAMS program also provides the opportunity for students to take their clinical rotations at off campus sites due to the ability to attend classes via interactive video conferencing.⁶¹ This allows students to get hands-on experience at additional clinical sites that may not necessarily be geographically affiliated with a genetic counseling training program, thereby addressing one of the barriers to genetic counseling program growth.

The Bay Path University master's in genetic counseling program, set to launch their first class in the fall of 2017, advertises their coursework as flexible and blended, by offering classes online and on-campus on the weekends.⁶² Similar to UAMS, this provides students with the opportunity to seek out clinical training sites that distance may have previously prohibited. Additionally, in recognition of the growing role for genetic counselors in nonclinical roles, Bay Path University has set up clinical rotation sites with two genetic laboratories for their students to gain in-person experience in a laboratory setting.⁶²

5.1.4 UK Genetic Counsellor Training

The specialized education and training for genetic counsellors in the United Kingdom began in 1992 with the formation of the first training program in Manchester, but prior to that time, genetic counselling services were offered by "genetics nurses" or "genetics social workers".⁹⁸ There are currently three genetic counselling training programs in operation in the United Kingdom.

The Genetic Counsellor Registration Board (GCRB), which was founded in 2002, is the organization in the United Kingdom that is responsible for establishing, maintaining, and improving the standards of practice for genetic counselling to assure public safety.⁹⁹ The GCRB sets and maintains standards for entry into the profession, establishes and maintains systems of accreditation, and establishes and improves the standards of professional practice⁹⁹, which echo the responsibilities of the ABGC, ACGC, and Canadian Association of Genetic Counsellors (CAGC) in the United States and Canada.

There are two paths toward GCRB registration as a Genetic Counsellor in the UK⁹⁸, which is similar to ABGC certification in North America. One must either graduate from an GCRB-accredited master's program or have graduated from a master's program with a professional certification as a registered nurse or midwife and complete training in genetics and counselling.⁹⁸ After a full-time training period of two years as a genetic counsellor in a GCRB suitable site under the supervision of a Registered Genetic Counsellor, one becomes eligible to apply for registration him/herself.⁹⁸ The two-year training period is government funded and includes a salary for the trainee and a stipend for the host department.⁹⁸ To apply for registration, a trainee genetic counsellor submits a portfolio documenting their successful attainment of the GCRB core competencies.⁹⁸ Genetic counsellors are required to re-register with the GCRB every 5 years.⁹⁸ Similar to ABGC certification in the United States, GCRB registration is recommended for most employment opportunities, but not required in the United Kingdom.¹⁰⁰

Another avenue for professional registration as a genetic counsellor is through the European Board of Medical Genetics (EBMG), whose mission is to establish standards for education, training, and practice in genetics and genetic counselling.¹⁰¹ Similar to the GCRB, there are multiple ways to register as a genetic counsellor, depending on an individual's educational background and professional work experience.¹⁰¹ For example, those who have graduated with a master's degree in genetic counselling and have worked full-time as a genetic counsellor for at least three years are eligible for EBMG registration, whereas individuals who have genetic counselling specific education and training without having attended a genetic counselling program must have worked as a genetic counsellor for four or more years.¹⁰¹ Professionals who did not have specific genetic counselling training must have worked as genetic counselling training must have worked as

Although GCRB and EBMG registrations are through two different organizations, they both offer genetic counsellors and other health professionals who provide genetic counselling services with the ability to obtain professional credentials. Unlike in the US, there is no board examination required in Europe in order to achieve credentials, but rather a portfolio of experience and letters of recommendations from professionals in the field.

There are two training programs in the UK that are GCRB accredited and offer a Master of Science (MSc) in Genetic and Genomic Counselling: University of Glasgow in Scotland and Cardiff University in Wales.¹⁰² These programs lead students toward the role of Registered Genetic Counsellor⁹⁹, which is similar to becoming a Certified Genetic Counselor in North America. A third program exists in the UK at the University of Manchester in England, but it is not GCRB accredited.

The University of Glasgow offers an MSc in Genetic and Genomic Counselling over a two-year period.¹⁰³ The structure is similar to that of the programs in the US in that it provides students with coursework and clinical training, as well as a dissertation.¹⁰³ The program also

advertises two electronic resources that students may access for additional teaching materials and self-assessments.¹⁰³

Cardiff University also offers an MSc in Genetic and Genomic Counselling, but at a parttime pace.⁹⁷ Interestingly, this is a three-year blended learning program and is largely completed online.⁹⁷ The focus of the first year is coursework, with two face-to-face meetings.⁹⁷ The second year includes some coursework, two face-to-face meetings, and a minimum of 72 days of clinical training at a location of the students' choosing.⁹⁷ The third year is dedicated to a student's dissertation, and has three face-to-face meetings.⁹⁷

Previously there was another MSc in Genetic Counselling program offered the University of Manchester, but it has since closed in favor of a new training program, the Health Education England (HEE) Scientific Training Programme (STP), for the role of Clinical Scientist-Genomic Counsellor.¹⁰² The STP is a full-time three-year training program that includes both academic and work-based learning.¹⁰⁴ If accepted into the STP, the student is actually employed full-time as a Trainee Scientist by the National Health Service (NHS) while they complete an MSc parttime at the location that trains their specialty, which for genetic counselling is the University of Manchester.¹⁰⁴ Though the first class, which was inducted in 2016, has not yet completed this training program, it is expected that they will have satisfied the necessary requirements to apply for GCRB registration, but it is still unclear as to whether these new graduates will register with the GCRB as Genetic Counsellors, with another professional organization as Clinical Scientists, or both.¹⁰⁵

Unlike traditional genetic counseling programs, the STP for Genomic Counselling does not accept a certain number of students per class, but rather commissions training posts each year based on the needs and projected future needs of the profession.¹⁰⁵ Importantly, this allows for the growth and needs of the genetic counselling profession to be considered alongside others in

the healthcare field.¹⁰⁵ On the other hand, this system has the potential to limit the number of genetic counsellors entering the field, although this is unlikely in the near future considering the current shortage of genetic counsellors. HEE, which is responsible for supporting the education of healthcare workers in response to the current growth of genomics, has recognized an urgent need to address the genomics training of health care professionals in the NHS.⁹⁰

By offering courses online and with a scientific focus as the Universities of Cardiff and Manchester are doing, the UK genetic counselling programs are also addressing workforce issues akin to what is being done in the US at UAMS and Bay Path University. Also similar to the US, though, is the lack of published evaluations regarding the impact of these changes on the genetic counselling workforce. Because of the dire need for more genetic counsellors in the field, it is important to perform targeted evaluations to determine what is effective and what is not, and how to implement successful changes in other genetic counseling programs to continue to grow the profession.

5.2 **PROGRAM EVALUATION**

5.2.1 Background

As genetics becomes more integrated into healthcare, genetic counseling training programs are continuing to increase in both size and number. Due to this growth, it is likely that there will be a greater emphasis on evidence-based education programs.⁸ In fact, one of the ACGC's requirements for accreditation is an annual evaluation of genetic counseling students and programs.³ On an annual basis, genetic counseling programs must report student performance on

the ABGC Certification Exam, alumni and employer survey data, personnel evaluations, course evaluations, clinical training evaluations, and student evaluations.³

"Evaluation" is a term that is loosely used to describe an assessment or review, but has a more specific meaning in the context of program evaluation.⁸ Program evaluation is the intentional and systematic collection of data about the various aspects of a program that can be used to make judgment about a program, improve a program, or develop future programs.¹⁰⁶ Although the ultimate goal of a program evaluation is usually to assess the impact of a program, it also seeks to answer the "how" and "why" questions about why the program worked or did not work.⁸ Therefore, an evaluation is not just the measurement of a program's ultimate impact, but rather is the framework in which the measurement occurs.⁸

In addition to answering questions about a program's outcome, program evaluations are important to conduct for a number of other reasons. For example, during the preparation of a program evaluation, one might learn more about the program's target audience and thereby better understand their needs and how to meet them.¹⁰⁷ Another benefit might be that a formal evaluation encourages evaluators to design program objectives that are both achievable and measureable.¹⁰⁷

When considering a program, there are three general points at which evaluations can occur. Formative evaluations occur at the beginning stages of a program, such as program planning and development.⁸ At this stage, evaluators generally engage with stakeholders to determine the program's needs, set goals for the program, and develop the structure or framework of the evaluation.⁸

The second point at which an evaluation can occur is during the execution of the program. This type of evaluation, known as a process evaluation, monitors how the program was implemented and whether or not it is reaching its target audience.⁸ If at this stage it is determined

that a program is deficient in some way, then it may be due to the fact that a rigorous formative evaluation was not carried out, or that the direction of the program should be rethought.⁸

The final point at which an evaluation can occur is at the end of a program. These summative evaluations assess the short and long-term outcomes of the program and judge its overall value.⁸ In order to do this, some form of comparison should be made, ideally to a control group, in order to understand the true impact of the program.⁸

When designing an evaluation, three main components should be considered: an evaluation question (which reflects the goals of the program), a comparison (to gauge potential impact or improvement), and a judgment (an overall assessment of the program's value).⁸ Despite this general outline, there is not a one-size-fits-all approach for program evaluations. Each program evaluation is situational, and it is important to build a framework that is specific to the program in question.⁸

5.2.2 Logic Models

To build the framework for a program evaluation, one can employ the use of a logic model.⁸ A logic model is an overview and depiction of how a program looks.⁸ Logic models allow evaluators to be explicit and to provide a rationale for each step of the process and prompt them to consider the interacting factors that contribute to the success or failure of the program.⁸

Logic models have five basic elements: resources/inputs, planned activities, outputs, outcomes, and impact.¹⁰⁸ These five elements can be grouped into two general categories: planed work and intended results.¹⁰⁸ Each element of a logic model is important, and is dependent on the element that precedes it.¹⁰⁸ For example, the success of the planned activities relies entirely on

the program's available resources. To highlight the interconnectivity of the pieces of the logic model, each of the elements is further described below.

The first basic element of the logic model is the resources, or inputs into the program.¹⁰⁸ This is a broad category and includes all of the assets of a program including program staff, financial support, supplies, and funding.¹⁰⁹ The second basic element of the logic model is the planned activity (or activities) that the program will use to achieve its desired outcome(s).¹⁰⁸ Together, the resources and planned activities describe the program's planned work.¹⁰⁸

The third element of the logic model describes outputs, or the direct results of the program's planned activities.¹⁰⁸ Outputs are usually quantifiable and can include types, levels, and targets of services.¹¹⁰ An example of a program output might be the number of students enrolled in a new educational program.

The fourth element of the logic model is the outcome, which is the observed change between the program's inputs and outputs.^{108,109} There can be short, medium, and/or long-term outcomes.¹¹⁰ Outcomes should be specific, measureable, action-oriented, realistic, and timed (SMART).¹⁰⁹ One example of an outcome could be increased SAT scores as a result of a new 3-month long educational program in a high school.

The fifth and final element of the logic model is the impact. Outcomes and impacts are sometimes confused, but a true program impact is the long-term change that is observed at the end of the program.¹⁰⁸ Using aforementioned example of increased SAT scores; a program impact could be that more students from that high school are accepted into college.

When constructed appropriately, logic models should clearly articulate the objectives of the program evaluation, name the desired results, and describe the strategy for achieving the program goals.^{8,108} Because they outline a group's shared understanding of how a program should work, they act as the foundation for a program evaluation.¹¹⁰

5.2.3 Significance to Genetic Counseling

An increasing number of genetic counseling programs are using online learning despite there being a lack of literature regarding evidence-based evaluations for online genetic counseling education.⁸ Much of what has been published is focused on the development and evaluation of genetics education programs for health professionals who are not genetic counselors, such as primary care physicians.⁸ Although these evaluations for non-genetic professionals are necessary and useful, it is also important to evaluate genetic counseling training programs to ensure that the field is working towards addressing the workforce shortage while maintaining the high standards of education required by the genetic counseling accrediting bodies.

Some training programs, like UAMS, Bay Path, and Cardiff have begun to branch out and utilize online learning for their students^{61,62,97}, which is relatively novel in the context of genetic counseling education. It is important to properly evaluate this online education modality because it has the potential to increase the number of clinical training sites by allowing students to utilize sites that are some distance away from the program while they complete the required coursework using online technology. Increasing the number of clinical training sites would address what many program directors feel is the greatest challenge to expanding genetic counseling education programs.⁸⁷

If successful, this educational approach may eventually have a positive impact on the genetic counseling workforce by increasing the number of trained professionals entering the field. This potential benefit to the genetic counseling profession supports a formal evaluation of online learning for genetic counseling students. Below, I propose a program evaluation and present a logic model to assess the effectiveness of online learning for genetic counseling students.

5.3 PROPOSED PROGRAM EVALUATION

5.3.1 Description

Online learning modalities are being increasingly used in genetic counseling programs in both the US and UK, despite a lack of published literature documenting their effectiveness. Because online learning has the potential to increase clinical training opportunities for students and ultimately grow the number of new genetic counselors entering the field, it is important to evaluate this pedagogical approach to ensure that it is at least as effective as traditional genetic counseling education programs.

In this evaluation, genetic counseling programs that offer at least 25% of their coursework online will be compared with genetic counseling programs that conduct coursework in a more traditional manner and offer less than 25% of their coursework online. Currently, ACGC accredited genetic counseling programs in the US and Canada must provide information about coursework provided online as part of their annual report to the organization. This information may be a useful source to help identify programs to include in this evaluation. A minimum of three genetic counseling programs will be recruited in each category, and at least one UK program must be represented in each category for an international perspective. Genetic counseling programs will be recruited to this evaluation via contact with the program directors.

The ultimate goal of this program evaluation is to better understand the effectiveness of online learning for genetic counseling students. To achieve this goal, knowledge and satisfaction data will be collected over the course of five years and generate a comprehensive report.

Student knowledge will be assessed in three different ways: knowledge assessments, which will measure student's ability to recall information, standardized patient encounters,

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which will measure student's ability to use learned information, and ABGC certification examination scores for US students and GCRB or EBMG registration rates for UK students, which will act as a standardized measure of a student's professional competency.

In addition to data regarding genetic counseling students' knowledge, satisfaction data will also be collected. These data will be used for the future development of new and existing genetic counseling training programs. This satisfaction data will be collected in the form of surveys and phone interviews with a small sample of students and program directors. Although satisfaction with the program is important, it is probably the least useful measure in an evaluation of program effectiveness because it does not necessarily reflect change.⁸

5.3.2 Logic Model

A proposed logic model for this program evaluation is depicted in Figure 1 and described in detail below.

| Situation | Inputs | Activities | Outputs | Outcomes | Impact |
|--|---|--|---|---|---|
| The issue | What we invest | What we do | What we generate | Short-Term (Years 1-3) Long-Term (Years 4-5) | What we achieve |
| Need/problem: Online learning modalities are being used more frequently in genetic counseling (GC) training programs. It is therefore important to evaluate this type of pedagogical approach to determine its effectiveness compared to that of programs that train students predominantly in the traditional classroom setting. Stakeholders GC students Program directors Program leadership Teachers/ supervisors GC's Employers Patients Professional groups | Program funding Equipment/ software for data collection and analysis Program staff salary/wages Staffing Project coordinator Data collectors Analysts Standardized patients Partners Participating GC programs NSGC AGGCD ABGC AGCPD EBMG GCRB GCWFWG | Determine extent to which online learning is being used by current GC programs Recruit GC programs to participate in this evaluation Create knowledge and satisfaction assessment tools Gather GC student and program director opinions about online learning Gather GC student and program director satisfaction data Gather AC student and program director satisfaction data Gather knowledge assessment and standardized patient encounter data for GC students Assess effectiveness of online learning for GC students by comparing knowledge and satisfaction between programs with ≥25% online classes and those with <25% online classes | Report on current use of online learning for GC programs Knowledge and satisfaction assessment tools Report of GC student and program director opinions about online learning Report of GC student and program director satisfaction data Report of Knowledge assessment and standardized patient encounter data Report of ABGC certification data Report of GCRB/EBMG registration rates Report of effectiveness of online learning | The knowledge assessment scores of students who attend a program with ≥25% online classes will be compared to those of students who attend a program with <25% online classes Performance in a standardized patient encounter for students who attend a program with ≥25% online classes will be compared to the performance of students who attend a program with <25% online classes Satisfaction with working in the field of genetic counseling will be compared between graduates who attended a program with <25% online classes ABGC Certification Exam scores will be compared between US graduates who attended a program with <25% online classes Satisfaction with online learning for students who attend a program with <25% online classes GCRB/EMBG registration rates will be compared between UK graduates who attended a program with ≥25% online classes GCRB/EMBG registration rates will be compared between UK graduates who attended a program with ≥25% online classes GCRB/EMBG registration rates will be compared between UK graduates who attended a program with ≥25% online classes | The effect of online learning on graduates' preparedness to practice genetic counseling will be better understood |

Evaluating Online Education for Genetic Counseling Training Programs

Figure 1: Logic Model

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5.3.2.1 Stakeholders

There are a number of stakeholders who should be included in a program evaluation for online learning. First and foremost are the genetic counseling students, program directors, and program faculty and staff who will be most directly impacted by both the education program and the evaluation. Given this direct impact, it is important to include these individuals from the beginning to ensure that the evaluation will provide them with information that they feel will be the most useful in evaluating their programs. Other important stakeholders to include as stakeholders would be professional organizations in the field of genetic counseling such as the NSGC, ACGC, ABGC, AGCPD, GCRB, EBMG, and the Genetic Counseling Workforce Working Group (GCWFWG). These organizations, though they fulfill individual and unique roles, are cumulatively responsible for upholding the integrity of the profession and ensuring an educated and competent genetic counseling workforce. Other stakeholders in the education of genetic counseling students include students' teachers and clinical supervisors, other healthcare professionals such as clinical geneticies, employers, and patients.

Because online learning has already been implemented to varying degrees among genetic counseling programs, it would be important to meet with stakeholders to conduct a needs assessment prior to beginning this program evaluation. During this needs assessment, the evaluation team should develop uniform standards by which students will be measured by seeking stakeholders' opinions. For example, curriculum topics for knowledge assessments, case studies for standardized patient encounters, and satisfaction-based questions should be decided prior to the implementation of the evaluation.

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5.3.2.2 Inputs

In order to successfully achieve the goal of this program evaluation, a number of resources, or inputs, will be required. Funding will be sought out in in the form of grants and be used to purchase computers and software with which to perform data analysis. Additionally, compensation will be necessary for program faculty and staff, including one project manager, data collectors, analysts, and standardized patients. Other resources for this program evaluation include stakeholder partnerships and the time investment from the stakeholders, as they bring unique knowledge and experience to the development and execution of the program.

5.3.2.3 Activities

In order to assess genetic counseling students' knowledge and satisfaction and ultimately the success of the online learning modality in their training, seven activities are planned over the course of a five-year program evaluation period. First, the extent to which online learning is being used by genetic counseling programs must be determined. It is important to know whether or not genetic counseling programs are utilizing online learning, what proportion of their courses are offered online, and what curriculum content has been selected for an online platform. These questions will be asked of genetic counseling program directors and other program leadership at the start of the needs assessment.

Next, genetic counseling programs will be recruited to participate in the evaluation by contacting program directors by way of email (such as the Association of Genetic Counseling Program Directors listserv) or by telephone. Because program evaluations are most effective when comparisons can be made⁸, programs that offer 25% or more of their coursework online will be evaluated alongside a control group of programs that offer less than 25% of their coursework online. A minimum of three different genetic counseling programs will be recruited

into each group, with at least one UK program in each group in order to offer an international perspective.

Based on the findings from the needs assessment, the program evaluators will create standardized assessments by which students will be measured. At the start of the students' first year of their genetic counseling program (year one of the evaluation), they will be given a baseline knowledge assessment in the form of a multiple-choice exam. After the completion of their first year, they will receive the same knowledge assessment and the scores will be compared to determine if they are able to recall the information that they had learned.

Near the start of the students' second year (year two of the evaluation), they will have a baseline encounter with a standardized patient. Because clinical experiences may differ between learning institutions, students should have acquired at least 20 patient experiences before their standardized patient experience. At the conclusion of the second year, during which students will have received some clinical training and direct patient experience, they will have a follow-up encounter with the standardized patient, which will measure the extent to which students can utilize learned information when interacting with a patient.

By the end of year three of the evaluation, recent graduates from the participating US programs will have taken the ABGC certification exam as a means to measure their professional competence. If programs that offer 25% or more of their coursework online are as effective in educating students as those programs that offer less than 25% of their coursework online, then students should be equally prepared to sit for the ABGC exam and the two groups should achieve similar average scores.

Because UK genetic counseling students apply for professional registration after two years of on-the-job training, we will measure the rates of GCRB or EMBG registration for UK students at the end of the fifth evaluation year. Programs that offer 25% or more of their coursework online should have similar rates of registration as programs that offer less than 25% of their coursework online.

In addition to gathering data to assess genetic counseling students' knowledge, satisfaction surveys will be distributed to genetic counseling students and program directors at the end of year three to gather their opinions of the use of online learning in genetic counseling education. Program evaluators will also conduct more in-depth telephone interviews with a smaller subset of students and program directors. The responses of these surveys and interviews will be used to inform ongoing and future program evaluations.

During year four of the evaluation, it is expected that most graduates of both the US and UK genetic counseling programs will be employed to some degree. US graduates will likely have been working for approximately one year, and UK graduates will be in either year one or year two of their trainee positions, depending on which genetic counseling program they attended. During this year, the program will survey these graduates to gather information about their satisfaction with the field of genetic counseling. In doing so, a better understanding of students' experiences after graduation will be achieved and similarities or differences between programs and/or countries can be documented.

The last activity planned for this educational assessment is to combine and analyze the data collected from the knowledge and satisfaction surveys to make a judgment about the effectiveness of online learning for genetic counseling students. These final results will be reported by year five of the program evaluation and will determine the overall impact of this particular educational approach on genetic counseling training.

5.3.2.4 Outputs

In a program evaluation, the outputs are the direct results of the planned activities.¹⁰⁹ The first output from this particular program evaluation will be a report on the current use of online learning for genetic counseling programs. This report will document which genetic counseling programs are using online learning and to what degree. This report will be used to identify the genetic counseling programs that will be invited to participate in the program evaluation based on the amount of online learning that their program offers.

The next output of this program evaluation will be the knowledge and satisfaction assessment tools. These tools will include multiple choice exams, standardized patient experiences, and satisfaction surveys. The program stakeholders will decide upon the content included in these assessment tools during the needs assessment stage of the program evaluation.

After the creation of the assessment tools, the remaining outputs from this program evaluation will be reports based on the data collected over the five-year evaluation period. These data sets will include: knowledge assessment data, standardized patient encounter data, ABGC certification exam data, GCRB/EBMG registration data, student and program director satisfaction data, and an overall evaluation of the effectiveness of online learning in the context of genetic counseling education.

5.3.2.5 Outcomes

A program outcome is the observed change between the program's inputs and outputs.^{108,109} To be of use, outcomes should be SMART: specific, measureable, action-oriented, realistic, and timed.¹⁰⁹ Three related SMART outcomes are expected from this program evaluation if genetic counseling programs that use a greater proportion of their coursework online are indeed as

effective in educating genetic counseling students as training programs that use more traditional classroom education.

By the end of year one, the team will have measured student knowledge for the students who attend a program with at least 25% online coursework and for those who attend a program with less than 25% online coursework. These data will be used to determine if there are any differences in knowledge between the two groups. Similarly, by the end of year two, the team will have assessed the data collected during the standardized patient encounters and compared the scores between the two groups of programs.

During year three, satisfaction surveys will be distributed to genetic counseling students and program directors to assess their opinions on and satisfaction with online learning experiences. The data from the two groups will be compared and analyzed for differences in reported satisfaction.

By the end of year three, US graduates will have taken the ABGC Certification Exam and the scores of the graduates who attended a program with at least 25% online coursework will be compared to those of graduates who attended a program with less than 25% online coursework.

During year four of the evaluation, another satisfaction survey will be distributed to new graduates who will be working in the field of genetic counseling. This survey will be designed to assess graduates' satisfaction with their work as a genetic counselor, and the results will be compared to determine if there are any differences in workplace satisfaction between graduates who attended a program with at least 25% online coursework and those who attended a program with less than 25% online coursework.

By the end of year five, UK graduates will have completed their two-year workplace training program and be eligible to apply for GCRB and/or EBMG registration. Since UK genetic counseling programs do not have a certification exam like the ACGC, the registration

rates of graduates from programs with 25% or more online coursework will be compared to those of graduates from programs with less than 25% online coursework to assess graduates' competence to practice as genetic counselors.

5.3.3 Impact

A program's impact is the long-term change that is observed years after the conclusion of the program.¹⁰⁸ Program impacts lead to changes in an organization or system and are generally considered to be the overarching goals of the program.¹⁰⁹ In evaluating the use of online learning to educate genetic counseling students, we hope to determine whether programs that employ a higher use of online learning in their coursework prepare genetic counseling students equally well for future professional practice as the programs that do not use as much online learning.

If this program evaluation is indeed effective in meeting this goal, it has the potential to inform genetic counseling education and training. Online learning for genetic counseling students could allow for more flexibility in the students' training schedules and provide them the opportunity to take advantage of more distant clinical rotation sites that may not have been previously accessible. The addition of more clinical rotation sites may indirectly, but positively address one of the greatest genetic counseling workforce challenges, by increasing the capacity of training programs to accept and educate more students.⁸⁷

5.3.4 Conclusion

Program evaluation is the systematic collection of data to judge a program, improve a program, or develop a program.¹⁰⁶ Because online learning is being increasingly employed by genetic

counseling programs around the world, it is important to formally assess the effectiveness of this training modality as compared to traditional genetic counseling education programs. Above, I propose a program evaluation that, if successful, will provide a better understanding of the current use of online learning in genetic counseling programs and potentially impact the genetic counseling workforce by increasing the number of trained professionals entering the field.

APPENDIX A: IRB REVIEW LETTER



University of Pittsburgh Institutional Review Board 3500 Fifth Avenue Suite 106 Pittsburgh, PA 15213 412, 383.1480 412, 383.1528 (fix)

To: Leslie Walsh

From: IRB Office

RE: Evaluating the Effectiveness of Online Learning in the Context of Genetic Counseling Education

Date: May 5, 2017

The above referenced project has been reviewed by the University of Pittsburgh Institutional Review Board and a determination has been made that this evaluation project does not meet the federal definition of research [45 CFR 46.102(d)].

APPENDIX B: FALL 2016 COURSE SYLLABUS

Behind the Scenes: Lessons from Laboratory Genetic Counselors

Course Contact: Tara R. Hart, MS, CGC (thart@genedx.com)

Week 1 - October 20, 2016

The Role of a Genetic Counselor at GeneDx Lecturer: Jessica Chonis, MS, CGC (jchonis@genedx.com)

Week 2 - October 27, 2016

Things to Consider When Ordering a Test Lecturer: Elizabeth Williams (ewilliams@genedx.com)

Week 3 – November 3, 2016

Application of Psychosocial & Management Skills in the Lab Lecturer: Linda Carey, MS, CGC (carey@bioreference.com)

Week 4 – November 10, 2016

Tools Used in Variant Interpretation (Part 1) Lecturer: Rebecca Latimer, MMSc, CGC (rlatimer@genedx.com)

Week 5 - November 17, 2016

Tools Used in Variant Interpretation (Part 2) / Anatomy of a Report Lecturer: Sarah Jackson, MS, CGC (sajackson@genedx.com)

Week 6 – December 1, 2016

Whole Exome Sequencing Secondary and Incidental Findings Lecturer: Aida Telegrafi, MS, CGC (atelegrafi@genedx.com)

Week 7 – December 8, 2016

Unique and Incidental Findings Lecturer: Margaret Bradbury, MS, CGC, MSHS (mbradbury@genedx.com)

Week 8 – December 15, 2016

Panel Discussion Panelists: Jennifer Hair, MS, CGC (jhair@genedx.com), Lindsay Rhodes, MS, CGC (Irhodes@genedx.com), Angie Thompson, MS, CGC (anthompson@genedx.com), Willonie Mendonca, MSc, MS, LCGC (wmendonca@genedx.com)

APPENDIX C: SPRING 2017 COURSE SYLLABUS

Behind the Scenes: Lessons from Laboratory Genetic Counselors

Course Contact: Rebecca Latimer, MMSc, CGC (rlatimer@genedx.com)

Week 1 – January 26th, 2017

The Role of a Genetic Counselor at GeneDx Lecturer: Brad Williams, MGC, CGC (brad@genedx.com)

Week 2 – February 2nd, 2017

Things to Consider When Ordering a Test Lecturer: Rebecca Latimer, MMSc, CGC (rlatimer@genedx.com)

Week 3 – February 9th, 2017

Application of Psychosocial Skills in the Lab Lecturer: Leah Williams, MS, CGC (leah@genedx.com)

Week 4 – February 16th, 2017

Tools Used in Variant Interpretation Lecturer: Sarah A. Jackson, MS, CGC (sjackson@genedx.com)

Week 5 – February 23rd, 2017

Variant Interpretation Part II & Anatomy of a Report Lecturer: Anita Shanmugham, MS, CGC, MPH (anita@genedx.com)

Week 6 – March 2nd, 2017

Whole Exome Sequencing, Secondary and Incidental Findings Lecturer: Tara Funari, MS, CGC (tfunari@genedx.com)

Week 7 – March 9th, 2017

Incidental and Unique Findings Lecturer: Margaret Bradbury, MS, CGC, MSHS (mbradbury@genedx.com)

Week 8 – March 16th, 2017

Panel Discussion Panelists: Jennifer Hair, MS, CGC (jhair@genedx.com), Lindsay Rhodes, MS, CGC (Irhodes@genedx.com), Angie Thompson, MS, CGC (anthompson@genedx.com), Willonie Mendonca, MSc, MS, LCGC (wmendonca@genedx.com)

APPENDIX D: DEMOGRAPHIC QUESTIONS

- 1.) Which genetic counseling program do you attend?
 - a. Emory University
 - b. University of Pittsburgh
 - c. Boston University
 - d. Indiana State University
 - e. Sarah Lawrence College
 - f. Other (please specify)
- 2.) What is your year in your genetic counseling program?
 - a. 1st year
 - b. 2nd year
 - c. Other (please specify)
- 3.) What is your age?
 - a. [Free text response]
- 4.) What is the highest level of education that you achieved prior to entering into your genetic counseling program?
 - a. BA/BS
 - b. MS
 - c. MD/PhD
 - d. Other (please specify)
- 5.) How many laboratory classes did you take as an undergraduate student?
 - a. [Free text response]
- 6.) How many laboratory classes did you take as a graduate student?
 - a. [Free text response]
- 7.) Have you ever worked in a laboratory outside of the classroom setting? If YES, for how long?
 - a. Yes
 - i. [Free text response]
 - b. No

- 8.) Have any of your clinical rotations for your genetic counseling program been in a laboratory setting? If YES, how long did you spend in the laboratory setting?
 - a. Yes
 - i. [Free text response]
 - b. No
- 9.) What is your current level of interest in working in a laboratory setting after graduating fro your genetic counseling program?
 - a. Very Interested
 - b. Interested
 - c. Neutral
 - d. Disinterested
 - e. Very Disinterested

APPENDIX E: STUDENT DEMOGRAPHICS

Table 12: Student Demographics

| | N = 36 |
|----------------------------|------------|
| | n (%) |
| Learning Institution | |
| Boston University – | 5 (13.9%) |
| Emory University – | 7 (19.4%) |
| Indiana State University - | 4 (11.1%) |
| Sarah Lawrence College - | 11 (30.6%) |
| University of Pittsburgh - | 9 (25%) |
| | |
| Year in Program | |
| 1 st Year - | 8 (22.2%) |
| 2 nd Year - | 28 (77.8%) |
| | |
| Mean Age | 25.6 years |
| | |
| Highest Level of Education | |
| BA/BS - | 31 (86.1%) |
| MS - | 3 (8.3%) |
| MD or PhD - | 2 (5.6%) |

Table 12 (Continued)

| Mean Undergraduate Laboratory Courses | 7.69 |
|---|------------|
| | |
| Mean Graduate Laboratory Courses | 1.08 |
| | |
| Laboratory Experience | |
| Yes - | 19 (52.8%) |
| No - | 17 (47.2%) |
| | |
| Mean Laboratory Experience | 3.89 years |
| | |
| Laboratory Rotation | |
| Yes - | 8 (22.2%) |
| No - | 28 (77.8%) |
| | |
| Mean Length of Laboratory Rotation | 4.32 weeks |
| | |
| Interest in Laboratory Genetic Counseling | |
| Very Interested - | 3 (8.3%) |
| Interested - | 14 (38.9%) |
| Neutral - | 16 (44.4%) |
| Disinterested - | 3 (8.3%) |
| Very Disinterested - | 0 (0%) |

APPENDIX F: PRE AND POST-LECTURE KNOWLEDGE QUESTIONS

Lecture 1: The Role of the Genetic Counselor at GeneDx

- 1.) Which of the following is a reason for a laboratory genetic counselor to review a case?
 - a. To evaluate consistency between clinical presentation and test ordered
 - b. To call the patient to verify documentation
 - c. To order additional testing, if necessary
 - d. All of the above are reasons for a laboratory genetic counselor to review a case
 - e. None of the above are reasons for a laboratory genetic counselor to review a case
- 2.) Which of the following is involved in the process of report writing?
 - a. Interpreting results in the context of the individual's clinical phenotype, previous test results, and family history
 - b. Reviewing literature
 - c. Providing tailored recommendations
 - d. All of the above are involved in the process of report writing
- 3.) What percentage of GeneDx genetic counselors work remotely?
 - a. Less than 10%
 - b. Between 10-25%
 - c. Between 25-50%
 - d. <u>More than 50%</u>
- 4.) How many unique identifiers does the College of American Pathologists require for a patient sample?
 - a. One
 - b. <u>Two</u>
 - c. Three
 - d. Four
- 5.) Which of the following is the most correct workflow for processing a NextGeneration Sequencing sample in the laboratory?
 - a. DNA extraction, Sequencing, DNA library preparation, Analysis
 - b. DNA extraction, DNA library preparation, Sequencing, Analysis
 - c. DNA library preparation, DNA extraction, Sequencing, Analysis
 - d. Analysis, DNA extraction, DNA library preparation, Sequencing

Lecture 2: Things to Consider When Ordering a Test

- 1.) What is the current first-tier test for a child with multiple congenital anomalies?
 - a. Karyotype
 - b. FISH
 - c. Microarray
 - d. NextGeneration Sequencing
 - e. Whole Exome Sequencing
- 2.) Which of the following is not true about FISH?
 - a. FISH is often used to detect aneuploidies
 - b. FISH is the preferred method for detecting balanced translocations
 - c. FISH can be used to detect microdeletions
 - d. FISH has a faster turn-around time than a karyotype
- 3.) In a patient with a clinical diagnosis of LQTS (for which pathogenic variants in multiple genes can cause disease), which test would be most appropriate?
 - a. Genotyping
 - b. Sanger Sequencing
 - c. <u>NextGeneration Sequencing Panel</u>
 - d. Whole Exome Sequencing
 - e. Whole Genome Sequencing
- 4.) In which of the following scenarios would you be most likely to order genotyping?
 - a. A fetus suspected of having a skeletal dysplasia
 - b. An infant whose whole exome sequencing was uninformative
 - c. A child with multiple congenital anomalies
 - d. A couple seeking preconception carrier testing
- 5.) Which of the following is the best specimen to submit from a patient who has had a bone marrow transplant?
 - a. Blood
 - b. Saliva
 - c. <u>Skin biopsy</u>
 - d. All of the above would be appropriate specimen types

Lecture 3: Application of Psychosocial Skills in the Lab

- 1.) According to the NSGC 2016 Professional Status Survey, what percentage of genetic counselors report satisfaction with their job?
 - a. 60%
 - b. 70%
 - c. 80%
 - d. <u>90%</u>

- 2.) In which of the following settings do the majority of non-clinical genetic counselors work?
 - a. University medical center
 - b. <u>Commercial diagnostic laboratory</u>
 - c. Research & development
 - d. Bioinformatics
- 3.) According to recent empirical evidence, which of the following does not contribute to a statistically significant increase in job satisfaction for genetic counselors?
 - a. Increased salary
 - b. Ability to work autonomously
 - c. Decreased patient contact
 - d. Ample administrative support
- 4.) Imagine that you are a genetic counselor at a commercial diagnostic laboratory. You receive a call from a client who is angry because their test is 3 days late. Which of the following counseling skills would you be LEAST likely to employ in your discussion with your client?
 - a. Contracting
 - b. Empathetic statements
 - c. Confrontation
 - d. Anticipatory guidance
- 5.) Imagine that you are a genetic counselor at a commercial diagnostic laboratory. You are in the process of writing a report, but you and the geneticist disagree on the classification of a variant found by whole exome sequencing. Which of the following counseling skills would you be MOST likely to employ in your discussion with the geneticist?
 - a. Deflection
 - b. Focused questions
 - c. Redirecting
 - d. Silence

Lecture 4: Tools Used in Variant Interpretation

- 1.) A nonsense mutation may result in:
 - a. Altered methylation
 - b. A triplet repeat expansion
 - c. Protein truncation
 - d. Altered promoter activity
- 2.) True or False: The ACMG provides concrete guidelines, and as such, all laboratories classify variants the same way
 - a. True
 - b. <u>False</u>

- 3.) Which of the following is not a population database?
 - a. 1000Genomes
 - b. Exome Aggregation Consortium (ExAc)
 - c. <u>Uniprot</u>
 - d. NHLBI Go Exome Sequencing Project (ESP)
 - e. All of the above are population databases
- 4.) Which database is not commonly used to determine if a variant is published?
 - a. Human Genome Mutation Database (HGMD)
 - b. Exome Aggregation Consortium (ExAc)
 - c. Google
 - d. Pubmed
 - e. Gene-specific databases
- 5.) Which piece of evidence does not support the pathogenicity of a variant?
 - a. The variant has not been detected in control cohorts
 - b. The variant is de novo
 - c. <u>The variant is tolerated in many species</u>
 - d. The variant is segregating with disease in a family

Lecture 5: Variant Interpretation Part II & Anatomy of a Report

- 1.) Which of the following options best describes the workflow for a WES sample from the time that it is received at the lab?
 - a. <u>Accessions, NextGen sequencing, Analysis, Variant interpretation, Report</u> <u>writing</u>
 - b. Accessions, NextGen sequencing, Variant interpretation, Analysis, Report writing
 - c. NextGen sequencing, Accessions, Analysis, Variant interpretation, Report writing
 - d. NextGen sequencing, Analysis, Accessions, Variant interpretation, Report writing
- 2.) Which of the following is NOT included in a report?
 - a. Accessions information
 - b. <u>CPT codes</u>
 - c. Clinical indication
 - d. Recommendations
 - e. Methods and limitations
- 3.) Which of the following is NOT reported in a typical exome report?
 - a. Pathogenic Variants in Genes Associated with the Reported Phenotype
 - b. Likely Benign Variants in Genes Associated with the Reported Phenotype
 - c. Variants in Genes Possibly Associated with the Reported Phenotype
 - d. Candidate Genes with Potential Relationship to the Reported Phenotype
 - e. Incidental or Secondary Findings

- 4.) Which of the following is a source from which a phenotype driven gene list could be generated?
 - a. <u>OMIM</u>
 - b. ExAC
 - c. Uniprot
 - d. 1000Genomes
 - e. ESP

Lecture 6: Whole Exome Sequencing, Secondary and Incidental Findings

- 1.) Which of the following would be best detected by WES?
 - a. Triplet repeat expansion
 - b. Copy number variant
 - c. Exonic missense variant
 - d. Hypermethylation
- 2.) Which of the following is NOT a reason to perform WES in trio?
 - a. To maximize sensitivity and specificity of variant calling and interpretation
 - b. To enable the identification of de novo variants
 - c. To determine the phase of variants
 - d. To increase the number of variants identified within a family
- 3.) Which of the following is NOT true of incidental findings?
 - a. <u>They are actively sought out by practitioners</u>
 - b. They arise outside the original purpose of the test being performed
 - c. They may be anticipatable
 - d. They may be unanticipatable
- 4.) Which of the following type of result would be reportable as part of the ACMG Recommendations for Reporting of Secondary Findings in Clinical Exome and Genome Sequencing?
 - a. The variant reveals a person's unaffected carrier status
 - b. The variant is highly medically actionable
 - c. The variant determines non-paternity
 - d. The variant results in susceptibility for common disease

Lecture 7: Incidental and Unique Findings

- 1.) A child has been recently diagnosed with an autosomal recessive disorder and was found to be homozygous for a variant in the LPIN2 gene. Parental studies show that the father is heterozygous for the variant, but the mother is negative for the variant. Which of the following is NOT a likely explanation for these results?
 - a. Non-paternity

- b. Allele dropout in the maternal sample
- c. The mother carries a large deletion in the region of this variant
- d. The child acquired a de novo variant on his maternal allele
- 2.) During the analysis of targeted microarray, an incidental finding of mosaic trisomy 8 is discovered. Of the following technologies, which would be the most appropriate to use to confirm this finding?
 - a. NextGeneration Sequencing
 - b. Whole Genome Sequencing
 - c. <u>FISH</u>
 - d. Karyotype
- 3.) A 2-year-old boy is referred for whole genome aCGH due to global developmental delays. During analysis, a partial deletion of the BRCA1 gene is identified. Which of the following statements about this incidental finding is the most correct?
 - a. This finding does not need to be reported because it is outside the original scope of testing.
 - b. This finding does not need to be reported because this gene is related to an adultonset condition.
 - c. This finding should be reported because it has immediate implications for this patient's medical management
 - d. <u>This finding should be reported because whole genome aCGH is not a</u> <u>phenotype driven test and all deleterious deletions/duplications should be</u> <u>reported</u>
- 4.) Which of the following statements about mosaicism is TRUE?
 - a. Mosaicism can only affect females (due to skewed X-inactivation)
 - b. Somatic mosaicism is heritable
 - c. <u>Mosaicism can be present at different levels in different tissue types</u>
 - d. Mosaicism only affects gametes

APPENDIX G: POST-LECTURE SATISFACTION QUESTIONS

- 1.) Please rate the quality of the speaker:
 - a. Excellent
 - b. Good
 - c. Average
 - d. Fair
 - e. Poor
- 2.) Please rate the clarity with which the information was presented:
 - a. Excellent
 - b. Good
 - c. Average
 - d. Fair
 - e. Poor
- 3.) Please rate the overall value of this lecture topic to your training:
 - a. Very Important
 - b. Important
 - c. Average
 - d. Somewhat Unimportant
 - e. Unimportant
- 4.) What topics would you like to hear more of within this lecture?
 - a. Other (please specify)
- 5.) What topics would you like to hear less of within this lecture?
 - a. Other (please specify)

APPENDIX H: POST-SERIES STUDENT SATISFACTION QUESTIONS

- 1.) I would recommend this learning experience to other genetic counseling students.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 2.) It was as easy to learn in this format as in a traditional (i.e. in-person) classroom.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 3.) I felt that this learning experience was as comfortable as in a traditional (i.e. in-person) classroom.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 4.) I felt that the instructors were invested in my success in this learning experience.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 5.) Communicating with my classmates and instructors in this learning format was as good as in a traditional classroom.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree

- 6.) I felt that this learning experience was valuable to my genetic counseling education.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 7.) I felt that this learning experience provided me with knowledge that I had not yet received as part of my genetic counseling training.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 8.) Were the expectations of the course reviewed with you in a clear and concise manner?
 - a. Yes
 - b. No
 - c. Somewhat
 - d. Other (please specify)
- 9.) What do you believe are the strengths of the GeneDx online course?
 - a. Other (please specify)
- 10.) What do you believe are the limitations of the GeneDx online course?
 - a. Other (please specify)
- 11.) Would you like to have additional:
 - a. In class discussions
 - b. In class activities
 - c. Hands on learning assignments
 - d. Other (please specify)
- 12.) Please share any other thoughts you may have about this learning experience:
 - a. [Free text response]

APPENDIX I: POST-SERIES PROGRAM DIRECTOR SATISFACTION QUESTIONS

- 1.) I feel that this learning experience was valuable to the student of my genetic counseling program.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 2.) I would recommend that future students in my genetic counseling program participate in this learning experience.
 - a. Agree
 - b. Somewhat Agree
 - c. Neutral
 - d. Somewhat Disagree
 - e. Disagree
- 3.) Please share any other thoughts you may have about this learning experience:
 - a. [Free text response]

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