Regional Challenges and Advances in Telegenetics During the COVID-19 Pandemic

by

Madeline Reding

BS Biology, BFA Creative Writing - Hamline University, 2017

Submitted to the Graduate Faculty of the
Department of Human Genetics
Graduate School of Public Health in partial fulfillment
of the requirements for the degrees of
Master of Science and Master of Public Health

University of Pittsburgh
2021

UNIVERSITY OF PITTSBURGH

GRADUATE SCHOOL OF PUBLIC HEALTH

This thesis was presented

by

Madeline Reding

It was defended on

June 14, 2021

and approved by

Robin Grubs, PhD, LCGC, Associate Professor of Human Genetics, Graduate School of Public Health, University of Pittsburgh

Patricia Documet, MD, DrPH, Associate Professor and Director of the Doctoral Program in Behavioral and Community Health Sciences, Director of Latinx Research and Outreach at the Center for Health Equity, Associate Professor of Clinical and Translational Science, Associate Director of the Evaluation Institute, Associate Professor at the Center for Latin American Studies, University of Pittsburgh

Alissa Bovee Terry, ScM, CGC, Genetic Services Outreach Coordinator and Telegenetics Navigator for the New York-Mid Atlantic Caribbean Regional Genetics Network

Thesis Advisor/Dissertation Director: Andrea Durst, MS, DrPH, LCGC, Assistant Professor of Human Genetics, Associate Director of the Genetic Counseling Program, Co-Director of the MPH in Public Health Genetics Program, Graduate School of Public Health, University of Pittsburgh

Copyright © by Madeline Reding

2021

Regional Challenges and Advances in Telegenetics During the COVID-19 Pandemic

Madeline Reding, MS, MPH

University of Pittsburgh, 2021

Abstract

During the COVID-19 pandemic, telehealth services were rapidly implemented to continue providing care to patients. The New York-Mid Atlantic Caribbean (NYMAC) Regional Genetics Network (RGN) has worked to facilitate the use of telehealth to improve access to genetics services in the region.

This study surveyed and interviewed NYMAC genetics providers to assess barriers and facilitators to the provision of telegenetics during the COVID-19 pandemic, the perceived value and demand for telegenetics services during this time, and any resources necessary to continue using telegenetics after the pandemic.

A 29-question survey was developed and distributed in July 2020 through multiple email listservs, receiving 169 responses. Among respondents, the most commonly reported barriers to telegenetics prior to COVID-19 were inadequate funding/billing/reimbursement (14% of selections; n=54) and lack of institutional support (12%; n=45). During the pandemic, workflow/logistical issues (22%; n=45) ranked most highly. Facilitators were similar before and during the pandemic, and included provider interest, patient interest and institutional support. Approximately 60% of respondents (n=48) said they planned to continue providing telehealth services after the pandemic while 7% (n=6) did not, showing uncertainty about the future of telegenetics in the region.

For the interviews, NYMAC TCOP leadership invited members to participate. Five genetics providers were interviewed, with each interview recorded and transcribed. Thematic analysis was performed and six themes and two sub-themes were identified: the Benefits of Telehealth; the Limitations of Telehealth (sub-themes: Social Factors and Patient Technology); External Factors; Evolving Models; Provider Adaptation; and Institutional Engagement.

Results show that NYMAC genetics providers had diverse experiences adapting to the COVID-19 pandemic, informed by prior experiences with telehealth, practice settings, patient populations, and chosen service delivery models. Even so, each participant described a role for telegenetics in the future, to retain the flexibility to meet patient needs and ensure broader access services. Participants described policies and resources that would facilitate the future use of telegenetics, including changes to licensure and reimbursement policies, CMS recognition of genetic counselors, and funding. This study is significant to public health because it indicates areas in which NYMAC and other organizations may provide support to telegenetics programs moving forward.

Table of Contents

List of Tables

List of Figures

Preface

Any year – but most especially, in this Year of the Flood – this project could not have come into existence, and I could not have attained this degree, without the help of many.

Thank you to my Committee chair, Andrea Durst, and to my Committee members, Robin Grubs, Alissa Terry, and Patricia Documet, for your kind and thoughtful guidance, your insight, and your patience. Thank you to the NYMAC Board for support and interest in this project, and to all of my survey and interview participants, for volunteering their time and experience. Thank you to Claire McDonald for being an incredible mentor and friend, and to Alyson Evans for showing me the ropes and answering my endless questions as a new NYMAC student worker.

Many thanks to my family for listening to my interests, these last two years and every year before; to my friends, Siri, Sydney, and Anna, for surprises in the mail, late Friday night Zoom sessions, and hope; to Midnight, for keeping me company on those very long writing days; and to Adam, my rock, for the endless encouragement, laughter, philosophical conversations, grilled cheese sandwiches, and clean dishes. I love you all immeasurably.

Acknowledgments

This work is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $2,400,000 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

Abbreviations

AAFP – American Academy of Family Physicians
ACMG – American College of Medical Genetics and Genomics
AHA – American Hospital Association
AJMC – American Journal of Managed Care
CDC – Centers for Disease Control and Prevention
CMS – Centers for Medicare and Medicaid Services
EHR – Electronic health record
EPHS – Essential Public Health Service
FCC – Federal Communications Commission
GAO – Government Accountability Office
HHS – Health and Human Services
HIMMS – Healthcare Information and Management Systems
HIPAA – Health Insurance Portability and Accountability Act
HPSA – Health Professional Shortage Area
HRSA – Health Resources and Services Administration
IRB – Institutional Review Board
Mbps – Megabits per second
MUA – Medically Underserved Area
MUP – Medically Underserved Population
NCC – National Coordinating Center
NSGC – National Society of Genetic Counselors
NYMAC – New York-Mid Atlantic Caribbean
RGN – Regional Genetics Network
TCOP – Telegenetics Community of Practice
USPSTF – United States Preventative Services Task Force
WHO – World Health Organization
WSRGN – Western States Regional Genetics Network

1.0 Introduction

In recent years, the field of clinical genetics worked to find new ways to provide patients access to genetics services. Some of the barriers to accessing genetics services that have been identified include too few genetic counselors, too few medical geneticists, and a maldistribution of health centers providing such services, with particular challenges to accessing services for those living in rural areas (Cooksey, Forte, Benkendorf, & Blitzer, 2005; Cosgrove et al., 2020; Maiese, Keehn, Lyon, Flannery, & Watson, 2019; Rhoads & Rakes, 2020). In the United States, there were about 3.5 clinical geneticists per 1 million people within the population in the year 2003. However, these geneticists were not evenly distributed throughout the country, with 17 states having too few medical geneticists to provide genetic services to their population (Cooksey et al., 2005). These disparities have persisted, with a survey distributed in 2015 revealing a maximum of 4.68 medical geneticists per 1 million people, which decreases to approximately 2 per 1 million when accounting for hours of non-patient care, as well as geneticists who have retired (Maiese et al., 2019). These numbers were similar in the Information on Genetic Counselor and Medical Geneticist Workforces report released by the U.S. Government Accountability Office (GAO) in July 2020 (Cosgrove et al., 2020). As a result of this shortage, nearly 40% of geneticists surveyed indicated that their institution had a wait time greater than 3 months for non-emergency, new patient appointments (Maiese et al., 2019). In particular, patients who lived in rural areas or on reservations, as well as those who did not speak English or who did not have health insurance, were identified as having the greatest barriers to accessing genetic services (Maiese et al., 2019). This is especially significant, given that almost 20% of United States residents live in rural areas (Rhoads & Rakes, 2020).

In addition to the geneticist shortage, there is also a shortage of certified genetic counselors who work with patients, though the number of jobs posted to the National Society of Genetic Counselors (NSGC) grew by 20% every year between 2013 and 2016. This shortage of clinical genetic counselors is expected to resolve between the years 2024-2030. However, other factors – such as an increase in the number of genetic counseling graduate programs, or a greater number of genetic counselors choosing to work in industry roles – may complicate this estimate (Hoskovec et al., 2018). The GAO estimates that there were about 14 genetic counselors per 1 million population in 2019, but reports that "There is no widely accepted measure for how many genetic counselors and medical geneticists should be available; however, representatives from professional organizations GAO interviewed stated that demand for genetic services is rising" (Cosgrove et al., 2020).

Telehealth, which is the provision of clinical care by using technologies to exchange information and communicate long-distance, has been suggested as a way to reduce barriers to accessing genetic services, particularly for patients who live in rural locations. Patient satisfaction with telehealth genetics (i.e. telegenetics) consultations is similar to in-person genetics appointments, and in some scenarios, patients prefer a telegenetics appointment (Rhoads & Rakes, 2020). Despite these advances, as of 2015, only 18% of all genetics providers reported using telegenetics, with a greater proportion of genetic counselors using telegenetics, at 20.8%, compared to geneticists, at 15.8% (Maiese et al., 2019).

In a survey of telegenetics providers within the New York-Mid Atlantic region (which, at the time of the survey, did not yet include Puerto Rico and the U.S. Virgin Islands), 56% of video conferencing telegenetics programs indicated an appointment wait time of less than 2 weeks, and 62% served patients who lived greater than 200 miles away (Terry et al., 2019). Although Terry et al. did not directly compare telegenetics and in-person services, these statistics indicate that there may be a larger reach and shorter wait times associated with telegenetics services compared to in-person services. The surveyed providers also indicated challenges to providing care via telegenetics. The largest barrier was professional licensure; other barriers included billing, engaging the referring providers and patients, and adequately providing psychosocial care to patients. To reduce these barriers in the future, the authors indicated the need for additional cooperation between healthcare providers, additional training in telehealth, and advocacy for telehealth policies (Terry et al., 2019). Barriers identified in other studies include the lack of resources, supporting regulations, professional support, technical equipment, and of perceived need for telegenetics services. Data security, particularly for patients receiving services to their homes, is an additional concern (Vrecar, Hristovski, & Peterlin, 2017).

Between January and March 2020, which was the beginning of the COVID-19 public health emergency, population-level interest in telehealth services increased, particularly in the Northeast region of the United States. However, existing capabilities were not sufficient to accommodate this new interest in telehealth services (Hong, Lawrence, Williams, & Mainous, 2020). A study examining US hospitals’ readiness to provide telehealth services found that rural hospitals are more likely to have existing telehealth capabilities than urban hospitals (Puro & Feyereisen, 2020). However, regional changes in the provision of telegenetics care during the COVID-19 public health emergency have yet to be described.

This study aimed to assess changes in genetics delivery models during the COVID-19 public health emergency. In particular, a survey of genetic providers within the New York-Mid Atlantic Caribbean (NYMAC) region evaluated the level of telegenetics implementation, challenges to implementing these services, and areas where additional help is needed. In addition, a qualitative interview of several genetic healthcare providers explored how previously identified barriers to providing telegenetics care existed during the COVID-19 public health emergency, and whether these factors influenced providers' intentions to continue providing telegenetics services in the future.

1.1 Specific Aims

AIM 1 (MPH Essay): Create and distribute an online survey for genetics providers to assess telegenetics use before and during the COVID-19 public health emergency, in collaboration with the NYMAC Regional Genetics Network, using other Regional Genetics Networks' telegenetics surveys as a guide.

AIM 2: Use the results of the online survey to create a list of interview questions to discuss with genetics providers. Analyze interview transcripts, using qualitative thematic analysis, to assess the following:

- Barriers and facilitators to the provision of telegenetics during the COVID-19 public health emergency
- The perceived value of and demand for telegenetics services during the public health emergency

AIM 3: Use the results of the survey and thematic analysis to determine what resources or policy changes may be necessary in order to continue providing such services after the pandemic.

2.0 Background and Literature Review

This discussion will begin with a description of barriers to accessing genetics services prior to the COVID-19 pandemic, followed by a description of the New York-Mid Atlantic Caribbean (NYMAC) Regional Genetics Network, its goals, and efforts towards those goals. Next, this review will introduce the reader to telehealth, as well as the benefits, facilitating factors, and barriers to the use of telehealth, prior to the COVID-19 pandemic. The final section will discuss the COVID-19 pandemic, detailing changes to the use of telehealth during this time.

2.1 Barriers to Accessing Genetics Services

Over the past twenty years, a number of barriers to patients accessing medically necessary genetics services have been described in the literature. These barriers include, but are not limited to, having too few geneticists and genetic counselors in the workforce, as well as geographical barriers including distance, maldistribution of genetics clinics, and living in rural locations (Cooksey et al., 2005; Cosgrove et al., 2020; Maiese et al., 2019; Rhoads & Rakes, 2020). This literature review will more fully describe these barriers, and elucidate the background and limitations around one possible solution – the use of telehealth to provide genetics services.

The Government Accountability Office (GAO) recently issued a report on genetic counselor and medical geneticist workforces, completed on behalf of a House Committee on Appropriations and provided to the Department of Health and Human Services and the Department of Labor. In this report, the GAO describes that in 2019, there were approximately seven genetic counselors per 500,000 people within the United States, and in 2020, there are about two medical geneticists per 500,000 people. While the GAO did not estimate the size of the workforce required to meet the needs of the population, it does say that its interviews with representatives from professional genetics organizations have indicated that the demand for genetics services has been increasing (Cosgrove et al., 2020).

Though the GAO did not make a direct judgment, a separate 2003 survey of geneticists certified with the American Board of Medical Genetics called the workforce situation "critical," at which point geneticist numbers were similar, with about 3.5 medical geneticists per 1 million people in the United States. The authors also noted an uneven geographic distribution, which meant that 17 states did not have enough medical geneticists to provide necessary services within the state (Cooksey et al., 2005). Indeed, the GAO described that the concentration of genetic counselors and geneticists is highest in northeastern states, a few midwestern states such as Minnesota and South Dakota, and some western states such as Utah, California, Oregon, and Washington. By contrast, there are fewer genetic counselors and geneticists in southern states, some midwestern states such as North Dakota and Kansas, and some western states such as Nevada and Arizona, with no geneticists reported to be located in Wyoming (Cosgrove et al., 2020). The current supply of genetic counselors is similarly lacking. A 2017 study estimated that the supply of and demand for genetic counselors will be approximately equal around 2024-2030, with approximately one full-time genetic counselor per 75,000-100,000 population (5-7 genetic counselors per 500,000 people), but noted that this may vary with the growth of existing training programs, the creation of new training programs, and changes in demand (Hoskovec et al., 2018).

In the context of the paper by Cooksey et al. and other such workforce studies, a recent study by Maiese et al., published in 2019, surveyed 924 genetics providers, including 249 medical geneticists and 536 genetic counselors. They reported that wait times for a new, non-emergency genetics appointment have increased, with 62% of geneticists reporting a one month or longer wait time, while the overall number of geneticists has remained stagnant (Maiese et al., 2019). While alternative service delivery models such as telehealth have been proposed and investigated as means of reducing barriers to genetic services, particularly for patients living in rural areas (Hilgart, Hayward, Coles, & Iredale, 2012), Maiese et al. reported that relatively few genetics providers - 20.8% of genetic counselors and 15.8% of geneticists – had provided services via telehealth at the time of their study (Maiese et al., 2019). By contrast, a separate 2017 study reported that in a survey of National Society of Genetic Counselors (NSGC) members, 68.3% of their 344 respondents had previously provided telehealth services, while about 31.6% had not. Furthermore, 92% of those who did not currently provide telehealth services were "at least slightly interested" in providing counseling services via telehealth (Zierhut, MacFarlane, Ahmed, & Davies, 2018). The true proportion of genetic counselors providing services via telehealth in this 2018-2019 time period is likely somewhere between 20.8% and 68.3%, and additional information regarding the wording of survey questions, the survey titles, and the descriptions provided in the emails that distributed them may help to parse out any possible effect of ascertainment bias.

In summary, barriers to accessing genetics services may include too few genetic counselors, too few medical geneticists, physical distance from genetics clinics, and relatively few genetics clinics providing services via telehealth, at least prior to the COVID-19 pandemic. As previously described, the number and distribution of genetics professionals can vary significantly in different geographical regions.

2.2 The New York-Mid Atlantic Caribbean (NYMAC) Regional Genetics Network

The Genetics Services Branch of the Health Resources and Services Administration (HRSA)'s Maternal and Child Health Bureau funds seven regional genetics networks (RGNs). These RGNs, each serving a region of the United States, work toward an over-arching mission "to improve access to quality genetic services for underserved populations" (NCC, 2020a). The New York-Mid Atlantic Caribbean (NYMAC) RGN serves the states and territories of Delaware, Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, the U.S. Virgin Islands, Virginia, Washington D.C., and West Virginia. In addition to the RGNs' over-arching goal of increasing access to genetics services, NYMAC also works to "Support a regional infrastructure for genetic services," to "Provide education and resources to families and providers," and to "Facilitate the use of telehealth in genetics" (NYMAC, n.d.-b). This study was conducted in collaboration with NYMAC to support these goals.

HRSA defines several shortage designations to be used by federal programs such as the RGNs, to help allocate resources and to identify areas of need. These shortage designations include Health Professional Shortage Areas (HPSAs), Medically Underserved Areas (MUAs) and Populations (MUPs). HPSAs are geographical areas, a specific population within a geographical area, or individual facilities, with too few primary care, dental care, or mental healthcare providers. The criteria for establishing HPSAs take into account the number of providers for the given population, poverty rates, and travel distance to the nearest source of care (HRSA, 2021). Another commonly used designation, MUAs describe geographical areas such as counties or ZIP codes without sufficient primary care services available; MUPs indicate a sub-population within a specific geographical area, for whom primary care services are not sufficiently accessible. MUAs and MUPs are established by taking into account the number of providers for the given population, poverty rates, the proportion of the population over age 65, and the infant mortality rate within that population or area (HRSA, 2021). These shortage designations provide useful information to NYMAC and other RGNs as they work to increase access to genetics services among underserved populations.

Within the NYMAC region, the ACMG Clinic Directory lists a total of 426 genetics clinics through its Find a Genetics Clinic Tool; however, these clinics are not equally distributed across the region. Figure 1 illustrates the distribution of genetics clinics to each of the NYMAC states and territories; the greatest proportion of genetics clinics are located in New York (31%), Pennsylvania (22%), and New Jersey (16%), with the fewest genetics clinics located in the U.S. Virgin Islands (<1%), Puerto Rico (<1%), and Delaware (1%) (ACMG, 2021).

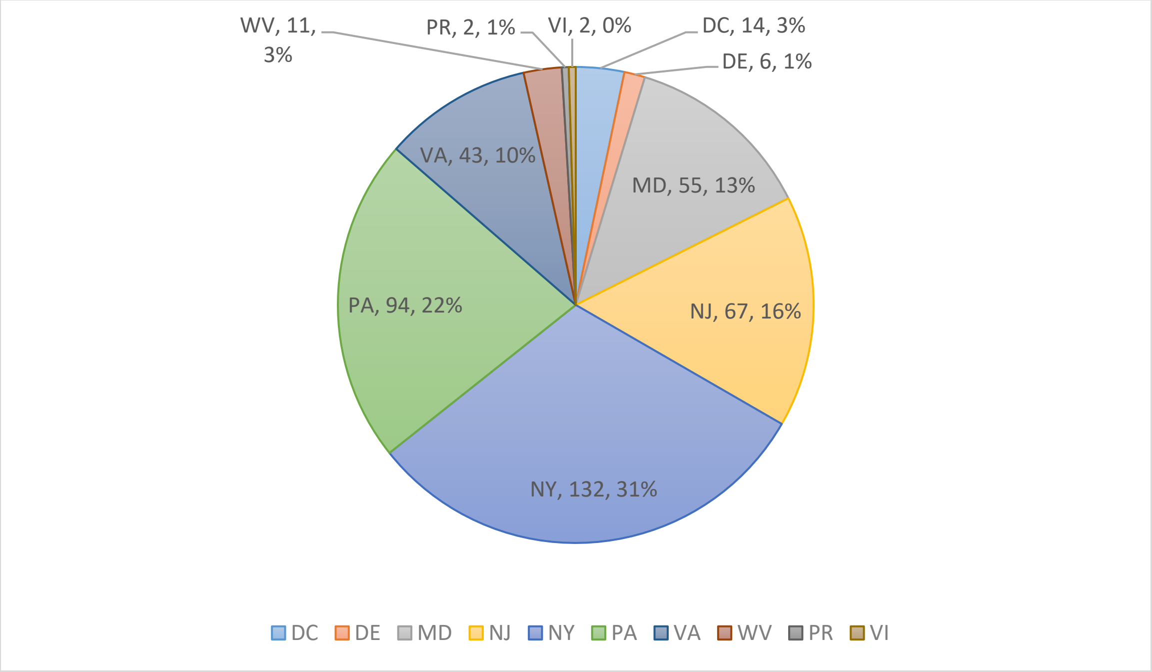


Figure 1. Distribution of Genetics Clinics Within the NYMAC Region.

However, in assessing the distribution of genetics clinics, it is also important to consider the size of the population served by clinics within that state or territory. Table 1 breaks down the number of genetics clinics, the population size, and the number of clinics per 100,000 people for each of the states and territories within the NYMAC region. To create this Table, the ACMG Find a Genetics Clinic Tool was used to estimate the number of genetics clinics within each state or territory, and each population estimate comes from the U.S. Census Bureau Population Estimates Program, representing populations in the year 2019, except estimates for the U.S. Virgin Islands, whose population counts come from the 2010 U.S. Census (ACMG, 2021; U.S. Census Bureau, 2010; U.S. Census Bureau Population Estimates Program, 2019).

On the whole, the NYMAC region has 0.682 genetics clinics per 100,000 people living within the region. Because of their relatively small population size, Washington D.C. and the U.S. Virgin Islands have the highest concentration of genetics clinics, with 1.984 clinics per 100,000 in Washington D.C. and 1.880 clinics per 100,000 in the U.S. Virgin Islands, though they had 3% and <1% of the total number of clinics within the region, respectively. By contrast, Puerto Rico had the fewest clinics per population, at approximately 0.063 clinics per 100,000 population (ACMG, 2021; U.S. Census Bureau, 2010; U.S. Census Bureau Population Estimates Program, 2019). It is also important to note that these are imperfect estimates based on the number of clinics as reported in the ACMG Find a Genetics Clinic Tool, and the true number of genetics clinics may not be accurately depicted, as is the case for the U.S. Virgin Islands, where there are currently no practicing genetics providers. The two clinics reported may instead refer to locations providing newborn screening services rather than clinics providing genetics services (Terry, May 25, 2021).

Overall, the proportion of genetics clinics per population within the states and territories of the NYMAC region appear to be consistent with the GAO’s description of genetic counselor and geneticist distribution being the highest in northeastern states. It is also worth noting that while estimates of total genetics clinics within each state or territory and the number of genetics clinics per population can be useful barometers in describing the availability of genetics services, these metrics do not capture the geographical distribution of clinics within each state or territory, nor barriers such as travel time to clinic or wait time for an appointment. Additionally, these estimates do not indicate how many genetics clinics are available in each specialty area.

Table 1. Genetics Clinics per 100,000 Population Within the NYMAC Region.

	Genetics Clinics	Population	Clinics Per 100,000
NYMAC Region	426	62,490,698	0.682
Delaware	6	973,764	0.616
Maryland	55	6,045,680	0.910
New Jersey	67	8,882,190	0.754
New York	132	19,453,561	0.679
Pennsylvania	94	12,801,989	0.734
Puerto Rico	2	3,193,694	0.063
U.S. Virgin Islands	2	106,405	1.880
Virginia	43	8,535,519	0.504
Washington, D.C.	14	705,749	1.984
West Virginia	11	1,792,147	0.614

This clinic distribution information reveals areas of need within the NYMAC region, which may supplement formal designations such as HPSAs and MUAs by providing information more specific to the genetics specialty area. Providing services via telehealth may be one way to connect patients living in areas with relatively few genetics clinics to medically necessary genetics services.

2.3 Introduction to Telehealth

As defined by the Health Resources and Services Administration (HRSA), telehealth is “the use of electronic information and telecommunication technologies to support long-distance clinical health care, patient and professional health-related education, public health, and health administration” (HRSA, 2020), while telemedicine refers more specifically to remotely providing clinical care to patients (AAFP, n.d.). Under these broad definitions, various modalities may be used to provide patient services. Most commonly, this may involve video conferencing or a telephone consultation between the patient and clinician. Store-and-forward methods may also be used, in which a clinician at one site collects information about the patient electronically, and the information is transferred to another clinician at another site to be reviewed not in real time. Telehealth services have traditionally been used to link one healthcare setting to another, such as when a patient arrives at a clinic (a “spoke” or “originating site”) to video conference with a clinician at another clinic location (the “hub” or “distant site”). However, it may also involve providing services via technology to patients in their own homes or other locations. In this paper, “telegenetics” will refer to the use of telehealth modalities, including video conferencing, phone consultations, and store-and-forward, to provide genetics services to patients.

Telemedicine technologies are evolving quickly in capability and cost, and include devices for remote monitoring, such as blood pressure cuffs, thermometers, digital scales, and metered dose inhalers. Some of these devices upload data directly for review by providers, and may be used in store-and-forward telehealth. Additionally, multiple vendors offer technology for video consultations, and newer and more advanced platforms may even combine remote monitoring and video consultation capabilities under the same platform (Baker & Stanley, 2018). One limitation of this type of combined platform is that hospital or clinic staff may need to be present at the “spoke” to use and clean the devices, requiring the use of a clinical “spoke” site rather than providing these services directly to patients’ homes (Baker & Stanley, 2018).

2.4 Benefits of Telegenetics

As previously described, telehealth has been suggested as a way to help increase access to genetics services (Hilgart et al., 2012) by addressing problems such as travel time and the geographic distribution of genetics professionals. Telehealth may also help to alleviate long wait times for genetics appointments (Maiese et al., 2019; Terry et al., 2019), and in some settings, can reduce the cost of providing genetics services to patients (Buchanan et al., 2015).

Telegenetics may be a useful tool to ameliorate access issues related to geographical barriers and workforce status. Within the NYMAC region, there does appear to be an unequal distribution of genetics clinics among the states (ACMG, 2021). While telegenetics cannot increase the number of genetics providers in the workforce, it may help to alleviate problems related to geographic distribution by connecting patients in underserved areas to genetics professionals remotely.

Additionally, it is possible that telegenetics may help to alleviate long wait times for new, non-emergency genetics appointments. In contrast to the long wait times for in-person genetics appointments described in the paper by Maiese et al., in which 62% of geneticists reported a wait time of at least one month (Maiese et al., 2019), a survey of telegenetics providers within the NYMAC region showed that 56% of clinicians providing services via video conferencing indicated that their wait time was less than two weeks. Their data also indicate that telegenetics may be a useful tool for overcoming geographic barriers and irregularities in the geographical distribution of genetics providers; 50% of clinicians providing services via video conferencing indicated some of their patients live greater than 200 miles away, and 59% provide services directly to patients' homes rather than through a spoke site (Terry et al., 2019).

In some settings, telegenetics may even lower the cost of providing services to patients. One randomized trial compared the cost of providing cancer genetic counseling services to patients in-person versus via telehealth. The hub-and-spoke model of telehealth used in the study required steep start-up expenses to purchase necessary equipment. However, when considering the number of patients who could be seen in the future with the same equipment, balanced against the time required for the genetic counselors to commute to distant satellite clinics, the cost of providing services via telehealth was less than half the cost of providing services to patients in-person (Buchanan et al., 2015).

2.5 Facilitators to Telegenetics

In addition to the previously described recent advances in telehealth technology (Baker & Stanley, 2018), potential facilitating factors for the expansion of telegenetics services include provider interest (Zierhut et al., 2018), the availability of training and support programs for providers (NCC, 2020b; NYMAC, n.d.-b; Terry, May 25, 2021; WSRGN, 2017), and positive patient response (Buchanan et al., 2015; McDonald, Lamb, Grillo, Lucas, & Miesfeldt, 2014; Solomons, Lamb, Lucas, McDonald, & Miesfeldt, 2018). Some of these facilitating factors may be modulated by the specific service modality in use (Voils, Venne, Weidenbacher, Sperber, & Datta, 2018). These factors will be discussed in more detail below.

Zierhut et al. described provider interest in their 2018 paper, in which they surveyed NSGC members regarding their experience with telegenetics. Of the 68.3% of respondents who had provided telegenetics services in the past, 69% identified the most appealing aspect of a remote genetic counseling position as “an innovative approach to healthcare delivery,” while 53% indicated “the ability to work from home,” and 50% indicated “flexible hours.” Among the 36.6% of respondents who had not used telegenetics, 65% indicated that the most significant draw was “an innovative approach to healthcare delivery,” 82% indicated “the ability to work from home,” 81% indicated “flexible hours,” and 56% “supplemental income.” Additionally, 91% of the group who had provided services via telegenetics indicated that they were “satisfied” or “very satisfied” with their work, and 92% of those who had not previously used telegenetics were “at least slightly interested” in providing telegenetics services (Zierhut et al., 2018). These positive perceptions of providing genetic counseling via telehealth, as well as the positive experiences of providers who have utilized telegenetics in the past, serve as facilitating factors that may draw providers to telehealth, or may encourage them to continue providing services via telehealth in the future.

In order to help facilitate the transition to providing more services via telehealth, the RGNs have created training tools for those genetics providers who are interested or motivated to do so. Western States Regional Genetics Network (WSRGN) accepts applications from healthcare providers to participate in their telegenetics training program; after selected, participants participate in a one-day in-person training, two webinars, and 10 online modules. Additionally, WSRGN provides support and other resources to past participants through an online bulletin board. Some of the overall goals of the WSRGN are to “Improve access to and reduce disparities in access to genetic services and education to medically underserved populations,” and to “Model and evaluate use of innovative service delivery methods, such as telegenetics, to improve access to genetic services . . . ” (WSRGN, 2017). NYMAC partners with WSRGN to offer telegenetics trainings within the NYMAC region. In addition, NYMAC offers support resources, webinars, grants for technical equipment and developing programs, on-on-one technical help, and a Telegenetics Community of Practice (TCOP) to facilitate relationships and support collaboration between telegenetics providers within the region (NYMAC, n.d.-b; Terry, May 25, 2021). The National Coordinating Center (NCC) for the Regional Genetics Networks reports that collectively, the RGNs trained 290 healthcare providers to use telehealth, provided education to 1,337 providers to introduce them to telehealth or to recruit them to the telehealth training program, and provided technical assistance to 42 providers from June 2013 to May 2014 (NCC, 2020b).

In addition to these provider-level factors facilitating the use of telegenetics, several studies have investigated patient experiences of telegenetics. One study surveying rural and urban Maine residents investigated how patients ranked different factors prior to attending a genetics appointment – in person vs. telehealth communication, provider expertise, personal vs. group genetic counseling, and local vs. distant location of services – from most to least important. The study found that the greatest proportion of respondents (70.4%) indicated provider expertise was their primary concern, while the fewest respondents (28.9%) indicated that local services were the most important to them. Preference for in-person services (29.1%) and personal rather than group counseling (31.5%) were similar to local services in their level of preference. In addition, rural and urban respondents did not have significantly different answers, despite different challenges to accessing these services (McDonald et al., 2014).

Another study, also centered in Maine, assessed satisfaction, understanding of hereditary breast and ovarian cancer predisposition syndromes, and feelings of anxiety and depression before and after cancer genetic counseling. The study compared patients receiving telehealth counseling to those receiving in-person counseling, finding that both groups showed improved understanding of hereditary breast and ovarian cancer, with no significant difference in the level of knowledge acquired between the two groups. While patients receiving telehealth counseling tended to have higher levels of depression prior to the counseling session, they also showed significant reductions in these levels of depression, while the patients receiving in-person services did not. In addition, although all patients indicated satisfaction with the counseling that they received, 32% of patients who had telehealth counseling would have preferred to have an in-person appointment. However, the group receiving telehealth services was distinct from the group of patients receiving in-person services in several ways: on average, they were older, more often lived in rural areas, and were less likely to have a college degree. The authors pointed out that the older average age, in the group receiving telehealth services, may have contributed to the preference for in-person services among 32% of the group (Solomons et al., 2018).

A randomized trial assessing patient satisfaction and attendance rates for cancer genetic counseling in-person versus via telehealth showed similar results. Patients assigned to the telehealth group and patients assigned to the in-person group showed high levels of satisfaction with no significant difference between the two groups, and there was no significant difference in the level of knowledge attained. However, there was a significant difference in attendance, with 89% of in-person patients attending their appointments, but only 79% of telehealth patients attending their appointments. The authors reflected that this lower attendance rate for telehealth appointments may have resulted in selection bias, elevating the satisfaction rates for telehealth appointments. Furthermore, 32% of patients who received counseling via telehealth indicated that they would have preferred an in-person appointment. Despite these limitations, the authors concluded that these results are encouraging, showing that telehealth appointments may be an acceptable alternative for the majority of patients in this setting (Buchanan et al., 2015).

Another randomized trial compared different modalities of telehealth services – phone vs. video conferencing – used to provide genetic counseling services. Both groups of patients reported high satisfaction with the counseling that they received. While the patients receiving phone counseling appreciated the flexibility and privacy of being able to attend their phone consult from home, tests of their knowledge before and after counseling showed very similar scores. By comparison, the group of patients receiving video counseling from a satellite clinic showed higher knowledge scores after counseling. The authors reflected that the lower level of knowledge acquired during phone consults may be related to genetic counselors' reports that their patients seen by phone are often less focused and less likely to ask questions than patients seen via video consult (Voils et al., 2018). In summary, facilitating factors for telegenetics vary, given the specific modality used to deliver services to patients.

2.6 Barriers to Telegenetics and Potential Solutions

Having considered benefits and factors facilitating the use of telegenetics, this section will describe barriers to widespread implementation of telegenetics services, and some strategies that may help to increase the provision of genetics services via telehealth. First, general barriers will be discussed, including issues relating to billing and reimbursement, provider licensure issues and CMS recognition of genetic counselors, and barriers related to patient technology literacy and cellular signals. An in-depth discussion of issues relating to high-speed broadband access will follow.

In addition to the positive aspects of providing services via telegenetics, Zierhut et al. asked their NSGC survey respondents about perceived and experienced barriers to telegenetics. Participants described problems such as “Inability or limitations to billing and reimbursement” (30.2% of respondents), “Proper equipment” (26.4%), “Technical issues” (21.4%), and “Coordination of care with local healthcare providers” (18.7%) in their responses (Zierhut et al., 2018). Despite facilitating factors that draw genetics providers to telehealth, these barriers may prevent the use of telegenetics.

Some of the same concerns were echoed by a working group made up of healthcare providers and formed by the American College of Medical Genetics and Genomics (ACMG) and the National Coordinating Center for the Regional Genetics Networks (NCC), which published a meeting report in 2009. This meeting report detailed some of the barriers to widespread implementation of telehealth modalities providing genetics services, as well as recommendations to help increase the availability of such services. In particular, the working group discussed challenges with provider licensure and credentialling, financing and reimbursement, and technology/delivery of services in detail (Shah et al., 2009).

In the United States, physicians must be licensed to practice medicine in the state where their patient is physically located at the time of service. This is an impediment to telehealth because while state licensure permits a patient to travel out of state to see a physician, it does not allow physicians to provide telehealth services to patients who are physically located in another state unless the physician also has licensure in that other state – which can be costly and complicated to obtain. The goal of these licensure requirements is to make sure that only competent, state-licensed doctors practice medicine in each state, though they also function to minimize competition from providers practicing in other states. Various solutions to this problem have been suggested, but not universally accepted and implemented. For their part, the ACMG working group recommended a multi-state licensure program for physicians providing telehealth services, with one application and streamlined rules for continuing education and application fees (Shah et al., 2009). There are a number of multi-state licensure programs now in existence to help address this problem.

In addition to these concerns about licensure requirements in the context of telehealth, problems related to financing telehealth services act as barriers. Costs associated with computer programming and equipment, as well as licensure and credentialling fees, can be prohibitive for hospitals looking to set up telehealth programs. At the time of the meeting, the working group described that while insurance reimbursement for telehealth services may be comparable to in-person services for some specialties, a minority of telehealth genetics programs receive funding from typical clinical billing, leading to concern that "all current telegenetics programs are dependent upon such time-limited funding" as contracts and grants (Shah et al., 2009). Billing practices may vary over time and by geographical region; ten years later, in a survey of telegenetics providers within the NYMAC region, Terry et al. reported that 47% of video-capable programs billed patients' insurance for their services (Terry et al., 2019). The other findings from this study echoed the ACMG summary of barriers to telegenetics in identifying professional licensure, billing issues, and trouble getting started as some of providers' most significant challenges to providing telegenetics services within the NYMAC region, but also added logistical issues, technology issues, and concerns about providing appropriate psychosocial care to patients (Terry et al., 2019).

Policies related to reimbursement for genetic counselor services, though they affect both in-person and remote services, can act as a key barrier to the adoption of telegenetics. Doyle et al. investigated reasons for limitations on insurance coverage of genetic counselor services by surveying medical directors and quality assurance directors of health insurance companies regarding the factors that went into their decisions about whether to cover genetic counselor services (Doyle, Cirino, Trivedi, & Flynn, 2015). The most significant barriers reported by their sample were “Evidence that use of genetic counselors improves health outcomes” (weighted mean of 4.3), “Practice guidelines of USPSTF or leading professional societies regarding incorporating genetic counseling into standard of care” (4.2), “CMS/Medicare recognition of genetic counselors as billable healthcare professionals” (4.1) and “Licensure of genetic counselors in our state” (4.0). The authors acknowledge that there are limitations to the potential generalizability of this data, given the small sample size (n=22) and the possibility for self-selection bias among survey respondents. However, they also suggest that this research may reveal additional areas for advocates to focus on when working to increase access to genetics services, and suggest that “NSGC licensure initiatives and efforts to make genetic counselors approved CMS providers will impact coverage policies overall” (Doyle et al., 2015).

A policy brief released by the NSGC details the relationship between the Centers for Medicare and Medicaid Services (CMS) recognition of genetic counselors as non-physician healthcare providers and access to telegenetics services. While genetic counselors are not required to be supervised by physicians in states where genetic counselors have licensure, current CMS coverage law does require physician supervision for compensation. Such law is a hindrance to providing genetic counselor services to the in-person patient population. “Direct supervision” of genetic counselors by physicians becomes even more logistically cumbersome, and potentially restrictive of patient access to genetic counselor services, in a telehealth context. The NSGC recommends legislative action to update CMS law through HR 2144 to allow CMS coverage of genetic counselor services, as a way of increasing patient access to genetics and telegenetics services (NSGC, 2021).

In addition to the above issues relating to billing, reimbursement, and licensure, efforts are underway to assess and address limitations around broadband and technology access in the home. DeGuzman et al. performed a feasibility study to assess a novel telehealth program for cancer survivors in rural areas of Virginia. Of the 19 cancer survivors in the study, participants with broadband access and the appropriate technology attended their telehealth appointment via video conferencing on their own devices; participants without broadband access, but within 30 minutes of a satellite clinic, drove to the satellite clinic; and participants without broadband access who lived greater than 30 minutes from a satellite clinic were mailed a tablet with cellular service to attend their appointment. Participants using the borrowed tablets encountered difficulty in accessing their appointments due to cellular signal and broadband speed limitations, and several participants using their own or borrowed technology required additional help from the research team and from their family members to access their appointment (DeGuzman et al., 2020). As they worked to assess other possibilities for patients to access telehealth appointments, the research team created a series of maps of the state of Virginia, revealing many areas lacking sufficient broadband access for patients to attend their telehealth appointments from home, and which were greater than 30 minutes away from a telehealth site. However, a map of Virginia indicating each public library revealed much greater coverage within 30 minutes from patients' homes, suggesting that a partnership with libraries may enable more rural patients to benefit from telehealth services (DeGuzman et al., 2020). DeGuzman et al.'s study reveals that in addition to broadband access, patient familiarity with technology, the ability of healthcare providers or other clinic staff to help patients troubleshoot, and the availability of family members to assist, may all influence how readily a patient can access telehealth (DeGuzman et al., 2020).

2.6.1 High-Speed Broadband Access

Lack of broadband access is very commonly included as a barrier to telehealth. In the Fourteenth Broadband Deployment Report of the Federal Communications Commission (FCC), released in January of 2021, the Commission outlines their current definitions for high-speed broadband access, arguing that “the current speed benchmark of 25/3 Mbps remains an appropriate measure by which to assess whether a fixed service is providing advanced telecommunications capability.” The FCC describes this as a functional definition, in which those who have broadband access at speeds of at least 25/3 megabits per second (Mbps) – indicating 25 Mbps upload speed, and 3 Mbps download – are able to upload and download video, audio, image, and other data. The FCC’s Household Broadband Guide indicates how minimum broadband speeds for a household may vary based on the number of users in a household, and the types of applications run. For example, a household that uses video conferencing applications such as those that may be used for telehealth is described as a Moderate Use household. For Moderate Use households with just one user, speeds of 3-8 Mbps are required, while a household with 2-3 users requires 12-15 Mbps (FCC, 2020b). Based on these figures from the FCC, the general 25/3 Mbps benchmark set by the FCC may or may not be sufficient for a given household to access telehealth services, depending upon the household’s other broadband needs.

An article collaboratively written by several researchers from the U.S. Centers for Disease Control and Prevention (CDC)’s Public Heath Law Program describes broadband access as “a super-determinant of health.” Not only does broadband access impact one’s ability to access healthcare services remotely via telehealth, the article explains, it also interacts with and influences other social determinants of health such as education and employment opportunities by impacting one’s ability to make use of online educational resources and training opportunities, online job listings and applications, and online business opportunities. Despite the importance of broadband internet access as a “super-determinant of health,” 24 million people in the United States live in areas without broadband access. This encompasses 19 million rural residents, as well as 1.4 million on Tribal lands – “rural and underserved populations who stand to benefit the most from telehealth,” as the article describes (Bauerly, McCord, Hulkower, & Pepin, 2019). These broadband access limitations pose a major roadblock for strategies that aim to use telehealth to increase access to genetics services. The authors continue to describe ways in which public policy can help or hinder the availability of broadband internet. In particular, federal agencies and state laws that provide funding for the expansion of broadband services or encourage investment into broadband expansion, as well as federal agencies collecting data regarding the availability of broadband services, have been helpful in continuing to expand access. They reference other state efforts such as encouraging public-private partnerships to expand broadband access, and placing broadband infrastructure at the same time as other infrastructure is being placed. By contrast, state laws limiting municipalities’ ability to expand broadband infrastructure independently inhibit the expansion of broadband access for their residents (Bauerly et al., 2019).

The FCC has also created a tool mapping broadband access in counties across the United States, called Connect2HealthFCC – Mapping Broadband Health in America 2017. The mapping tool indicates the proportion of the population in each county with access to broadband service with a speed of 25/3 Mbps or higher (FCC, 2017). Because this study aims to describe changes in telehealth within the NYMAC region, this review describes the proportion of each NYMAC state or territory with high-speed broadband access. The FCC reports that in each county in Delaware, at least 80% of the population has access to broadband service. The same is true for New Jersey and Washington D.C., indicating that while the majority of these states do have access to high-speed broadband services that may be sufficient for accessing telehealth services, as much as 20% of the population in these states may not have access to broadband at 25/3 Mbps. Additionally, each Maryland county has at least 80% access, except for two counties with 60-80% of the population having broadband access. While the majority of New York counties have at least 80% access, a handful have 60-80% access, and one New York county is reported having broadband access for only 20% of its residents, indicating inadequate broadband access for a significant proportion of the population within some of these counties. Similarly, the majority of Pennsylvania counties have at least 80% access, but a significant proportion of the state has less than 80% access, with two counties reported having broadband access for only 20-40% of their population. The state of Virginia is split, with most of its northern counties having broadband access for 80% or more of the population, but many southern counties reporting access for 60% of the population or less. The majority of West Virginia counties were also reported having broadband access for less than 60% of the population (FCC, 2017, 2020b, 2021). These data indicate areas of the continental U.S. NYMAC region where telehealth services relying on patients' access to broadband from their homes may hinder efforts to improve access to genetics services. These maps are available in Appendix D, Broadband Access Maps, in Appendix Figures 1-8.

The Connect2HealthFCC tool did not report broadband access for Puerto Rico or the Virgin Islands. However, the Federal Communications Commission Fixed Broadband Deployment tool, which indicates the number of service providers providing broadband access at speeds of at least 25/3 Mbps within each county or census tract, does provide 2019 data for these territories. These maps, available in Appendix D. Broadband Access Maps, Figure 9, show that the majority of census tracts in Puerto Rico have at least 3 broadband service providers available who can provide broadband speeds of 25/3 Mbps, while in the U.S. Virgin Islands, each census tract has 2 broadband service providers available with services at 25/3 Mbps (FCC, 2020a). However, while the maps in Figures 9 and 10 show the general availability of high-speed broadband service providers at the level of counties or census tracts, they do not indicate variability within those counties and census tracts, nor do they indicate adoption of broadband service. Based on these data, it is not possible to estimate the actual proportion of the population with access to high-speed broadband services from their own homes, and therefore it is uncertain whether efforts to increase the availability of telehealth services connecting to patients at their homes may actually increase the overall accessibility of genetics services within these territories.

Broadband access in the United States – and within the NYMAC region – will continue to evolve and shape the way that patients are able to access telehealth services. The White House Briefing Room issued a statement in March of 2021 detailing prospective legislation titled “The American Jobs Plan.” As part of this new legislation, the White House proposes to strengthen infrastructure, including establishing high-speed broadband access across the United States, with the goal of connecting the 35% of Americans in rural areas who lack high-speed broadband to broadband services at speeds of 25/3 Mbps ("FACT SHEET: The American Jobs Plan," 2021).

2.7 The COVID-19 Epidemic and Telehealth

In January 2020, the World Health Organization (WHO) identified a cluster of infections similar to pneumonia, possibly caused by a novel coronavirus (AJMC, 2020). Later identified as Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), or COVID-19, the virus originated in Hubei, China in December 2019 (Esakandari et al., 2020). The virus spread quickly, with the first case in the United States confirmed on January 21, 2020 (AJMC, 2020). COVID-19 was declared a pandemic by the World Health Organization on March 11 (AJMC, 2020), after which travel restrictions, city lockdowns, and social distancing guidelines were established in many states and cities across the United States.

Patient utilization of healthcare services changed at the beginning of the COVID-19 pandemic. A study by the U.S. Centers for Disease Control and Prevention (CDC) compared emergency department visits at the beginning of the COVID-19 pandemic to the same four-week period in 2019. The study found that there were 42% fewer emergency department (ED) visits from March 29 to April 25, 2020 compared to March 31 to April 27, 2019. This trend was even more pronounced in the northeastern United States, at 49% fewer ED visits during this time period. In addition, while there were more ED visits related to infectious diseases including COVID-19 in the spring of 2020, there were fewer ED visits due to chest pains, migraines, muscle pains, and abdominal pain. This may indicate that patients avoided going to the ED for treatment, even for concerning symptoms that could lead to significant morbidity and mortality, due to concerns for contracting COVID-19 (Hartnett et al., 2020).

The COVID-19 pandemic significantly challenged the capacity of existing telehealth resources and shifted the pre-existing benefits and barriers of telehealth. One study analyzing both the volume of Google searches for telehealth services from January 21, 2020 to March 18, 2020, and the proportion of hospitals offering telehealth services as reported in the 2018 American Hospital Association Annual Survey, found no correlation between population interest in telehealth services and the actual number of hospitals offering such services. The researchers suggested this may indicate inadequate existing telehealth infrastructure to meet the demands for telehealth services during the pandemic (Hong et al., 2020). While the study may be limited by its comparison of telehealth demands after the beginning of the COVID-19 pandemic to available telehealth services in 2018, this is a useful assessment of the suitability of existing telehealth infrastructure to accommodate sudden new demands for telehealth services.

Some clinics have published summaries of their experience in adapting to COVID-19 and transitioning to providing care through telehealth. For example, the Columbia University Irving Medical Center in New York City describes how their Reproductive Genetics clinic transitioned to providing all outpatient services via telehealth over the course of five days (March 12-17). They surveyed their staff each week and found that at the second week, 91% of clinicians felt that they were providing quality care, which increased to 100% by the fourth week of providing outpatient services entirely through telehealth. They describe some of the needs that arose, such as requiring administrative assistants to help patients log in to their appointments, translators for patients who do not speak English, and the flexibility to switch from video conferencing to a phone call as necessary for patient access. They also describe benefits of telehealth, including seeing patients out-of-state, once licensure restrictions were relaxed; better focus and less patient anxiety about blood draws or invasive prenatal testing following the appointment; and increased participation of other family members in the session. Indeed, as many as 50% of the patients they surveyed indicated that they would prefer telehealth over an in-person appointment regardless of the pandemic. Yet, not all patients were able to benefit, with a significant proportion of the population lacking Internet access. Further, patients were not always focused on their appointment, and physical exams were limited by video capabilities (Pereira et al., 2020).

Another paper described lessons learned from the same medical center’s efforts to provide obstetrical counseling via telehealth, consolidating in-person appointments throughout the pregnancy to reduce COVID-19 exposure risk for pregnant women in New York City. Obstetricians, maternal-fetal medicine specialists, psychologists, cardiologists, neurologists, and genetic counselors were among the healthcare professionals providing services via telehealth, with each provider receiving training via a 15-minute tutorial during the week prior to initiating telehealth services. The authors noted that this service delivery change required additional changes in workflow – for example, rather than drop off samples to the lab on their own, genetic counselors working from home via telehealth had to coordinate with hospital support staff who were still working on location. While the telehealth format seemed to be helpful for women who had to work from home, as well as for those who had additional childcare responsibilities due to school or daycare closures, there were other concerns about privacy. In particular, women considering pregnancy termination or experiencing domestic violence may not be able to discuss these matters freely while at home (Aziz et al., 2020).

2.8 Gaps in the Literature

While a handful of clinics have had the ability to transition to telehealth and even analyze and report statistics about their own experience during the pandemic, not all such experiences will make it into the literature, and our understanding of clinics' and clinicians' efforts to transition to telehealth, their unmet needs, the benefits and limitations of telehealth, and the existence of any disparities in access to such services is still largely unknown. Through a survey of genetics professionals within the NYMAC region, we aim to further collect and describe this information about clinics in the region, including whether they were successful in implementing telehealth genetics services in response to COVID-19, barriers to implementation, facilitators in implementation, and whether their institutions are planning to continue these services after the COVID-19 public health emergency. Interviews of genetics providers within the region will provide a deeper understanding of various genetics providers' perspectives on providing services via telehealth in the midst of a global pandemic. Conducted in partnership with NYMAC, the findings from this project will be useful to NYMAC as well as to public health organizations, hospitals, and other RGNs to design effective telegenetics support and resources for clinics, clinicians, and patients, as well as to advocate for policy changes necessary to increase access to telegenetics services for patients within the NYMAC region and beyond.

3.0 Public Health Essay

3.1 Background

On March 11, 2020, the World Health Organization declared a COVID-19 pandemic. The COVID-19 virus had originated in the Hubei province of China in December of 2019 and spread rapidly, with the first case in the United States confirmed on January 21, 2020 (AJMC, 2020; Esakandari et al., 2020). After the WHO declaration, cities and states within the U.S. established travel restrictions, city lockdowns, and social distancing guidelines to control the spread of the virus. Concerns about the virus lead to significantly fewer patients seeking care in emergency departments (Hartnett et al., 2020). Google searches for telehealth services rapidly increased, possibly beyond the existing capacity of hospitals to provide such services (Hong et al., 2020). Despite this lack of existing infrastructure for telehealth, healthcare services were rapidly moved to remote platforms, including video conferencing and telephone consultations between patients and their clinicians.

In the field of genetics, researchers have long investigated telehealth as a way to increase access to genetics services for medically underserved patients and patients living in rural areas (Hilgart et al., 2012; McDonald et al., 2014; Solomons et al., 2018). Other access barriers which telehealth may help to address include the size of the workforce, geographical barriers, and the maldistribution of genetics clinics (Cooksey et al., 2005; Cosgrove et al., 2020; Maiese et al., 2019; Rhoads & Rakes, 2020).

Despite the potential benefits of providing genetics services via telehealth, a number of barriers exist to the use of telehealth as well. Prior to the COVID-19 pandemic, such barriers have included problems with billing or inadequate reimbursement for services provided via telehealth; issues with licensure and credentialling, especially across state borders; not having adequate technical equipment, especially for a “distant site” or “spoke” site; problems with the logistics of a remote appointment; concerns about whether psychosocial concerns can be adequately addressed in a remote setting; and difficulties with patients’ technology access and capabilities (DeGuzman et al., 2020; Shah et al., 2009; Terry et al., 2019; Zierhut et al., 2018).

During the COVID-19 pandemic, some of these concerns seem to have shifted. In providing telegenetics services directly to patients’ homes during this time, some providers experienced fewer barriers related to licensure, as some states relaxed licensure restrictions to allow established patients to access services with their out-of-state provider remotely, rather than travel to a state where that provider is licensed (Shur et al., 2021). Additionally, questions regarding potential differences in clinical decision making due to the limitations of remote physical exams, have arisen (Shur et al., 2021). Some genetics clinics have described new or newly apparent difficulties their patients have experienced, such as inadequate Internet access, a lack of privacy when making difficult decisions, and difficulty accessing or using interpreter services, as well as benefits to patients of telehealth appointments, such as less anxiety, the presence of support persons, not needing to take time off work, and not needing to find childcare in order to attend the appointment remotely from home (Aziz et al., 2020; Pereira et al., 2020; Shur et al., 2021).

Regional genetics networks such as NYMAC, which serves the states and territories of Delaware, Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, the U.S. Virgin Islands, Virginia, Washington D.C., and West Virginia, have long been working to facilitate the use of telehealth genetics services as a way to advance their goal of increasing access to genetics services for underserved patients (NYMAC, n.d.-a). This survey project, performed in partnership with

NYMAC, seeks to learn from the rapid implementation of telehealth during the COVID-19 pandemic by identifying barriers and facilitators to the use of telehealth in the field of genetics during this time period, how these barriers and facilitators varied among clinics within medically underserved areas, and what additional resources may be necessary to support the continued use of telehealth in the field of genetics. This information will be helpful to NYMAC and other regional genetics networks as they work to provide resources and advocate for providers offering telehealth services.

3.2 Research Questions

The online survey addressed three primary research questions:

1. What were the barriers to using telegenetics before the COVID-19 pandemic, compared to during the COVID-19 pandemic?
2. What factors helped to facilitate the use of telegenetics modalities during the COVID-19 pandemic?
3. How did these barriers and facilitating factors differ in medically underserved areas?

3.3 Methods

3.3.1 Ethical Considerations

The protocol for this study was approved by the University of Pittsburgh Institutional Review Board (IRB) as an exempt study on June 24, 2020. An updated IRB submission with an adjusted introductory script to the survey was approved on June 29, 2021, still as an exempt study. The IRB approval letters are attached in Appendix A.

3.3.2 Creating the Survey

The NYMAC Telegenetics Survey was written in collaboration with the Leadership Committee for the New York-Mid Atlantic Caribbean (NYMAC) Regional Genetics Network, expanding on examples of surveys previously written and distributed by the Heartlands and Western States RGNs. All three surveys were targeted towards genetics providers, including genetic counselors and geneticists. Because the NYMAC survey specifically targeted genetics providers practicing within the region, additional questions were added to the beginning of the survey to assess each respondent's region of practice. Respondents who indicated that they practiced outside of the NYMAC states and territories (Delaware, the District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, the U.S. Virgin Islands, Virginia, and West Virginia) were directed to the end of the survey.

Survey questions were also added or edited based on the specific aims of the NYMAC survey, as described above. While the Heartlands and Western States surveys did not distinguish between different telehealth modalities, the survey for this study sought to gather information about the different telehealth modalities being used before and during the COVID-19 pandemic, and therefore added additional questions and options for providers to reflect their use of in-person, video conferencing, telephone consultation, and store-and-forward methods of service delivery. Additionally, the NYMAC Telegenetics Survey was designed to elicit one response per clinic, asking each survey respondent to answer each question as it applied to their clinic as a whole.

After making these changes, the NYMAC Telegenetics Survey consisted of 29 questions with an approximately 10-minute completion time. The survey was coded into Qualtrics, with IP addresses automatically removed for de-identification. The NYMAC Telegenetics Survey also linked to a second survey for providers who wished to opt-in to an informational interview, or to receiving additional telegenetics support services from NYMAC, by providing their email address. A copy of the introductory text, the NYMAC Telegenetics Survey, and the Opt-In to Telegenetics Assistance or Interview Survey are included in Appendix B.

3.3.3 Survey Distribution

The NYMAC Telegenetics Survey was distributed through the following professional organizations' listservs in July 2020: NYMAC directory and email lists; the NYMAC Telegenetics Community of Practice (TCOP); the National Society of Genetic Counselors; and the State Genetics Provider Groups for New York, Maryland (including Washington, D.C.), Virginia, Pennsylvania, and New Jersey.

The NYMAC directory was previously compiled in November 2019 and contains the email addresses of medical geneticists within the NYMAC region. Other email lists from NYMAC include the Meeting Invitee List and Attendees, as well as the regional clinic directory created by NYMAC for the ACMG "Find a Clinic" tool. Additionally, NYMAC created a Telegenetics

Community of Practice (TCOP) in 2016 to connect genetics providers who offer services via telehealth and to foster collaboration and mentorship between them. NYMAC hosts webinars and conference calls for the TCOP (NYMAC, n.d.-c). These internal listservs and the TCOP listserv were used to distribute the survey directly from NYMAC.

The NSGC distributed the NYMAC Telegenetics Survey in its weekly digest email, as part of the Student Research Survey Program. The survey was first distributed to NSGC membership through the weekly digest email on July 8, 2020, with a reminder on July 22, 2020. Though the NSGC membership is national, the introductory text in the email specified that the survey was geared toward genetics professionals working within the NYMAC region, and the survey itself only allowed respondents to complete the survey if they reported practicing within one or more NYMAC states and territories.

Finally, NYMAC leadership reached out to State Genetics Provider Groups for New York, Maryland (including Washington, D.C.), Virginia, Pennsylvania, and New Jersey. These groups agreed to distribute the survey to their membership, but exact timing is unknown.

3.3.4 Analysis

Descriptive statistics were performed and figures created using Qualtrics and Microsoft Excel. Microsoft Word and Microsoft PowerPoint were used to add labels to figures as appropriate. To increase the sample size as much as possible, partial answers were included in the analysis.

The ZIP codes entered by survey respondents were used to determine whether that response represented a Medically Underserved Area (MUA). An internal tool created by NYMAC, the MUAP ZIP Code Lookup Tool, was used to automatically classify each response as “MUA” or “not MUA” according to HRSA’s MUA designations (HRSA, 2021, n.d.).

3.4 Results

3.4.1 Survey Response Overview

The survey received 169 responses in total, with 91 respondents (54%) completing the entire survey. Of these, four responses (2% of total) were from respondents who did not report practicing within the NYMAC region, and therefore "finished" the survey by being sent to the end. An additional 29 respondents (17%) completed approximately half of the survey. While we initially suspected that some of these respondents completed half of the survey questions due to survey logic that directed them to skip certain questions, a closer look at the data indicates that respondents following survey logic were still listed as having "finished" the survey. This suggests that respondents who completed approximately half of the survey questions actually navigated away from the survey. The remaining 49 respondents (29%) quit the survey at question two, when asked for the ZIP code of their primary clinical practice.

Figure 2, below, illustrates the distribution of respondents' clinical practice locations. Respondents were directed to select all states or territories in which they provide genetics services, and there were a total of 164 respondents making 182 selections. The greatest number of respondents (n=51) reported practicing within the state of New York. By comparison, there were very few responses from Puerto Rico (n=1) and the Virgin Islands (n=0). Overall, the distribution of responses appears to be fairly representative of the number of clinics within each of the states and territories shown in Figure 1.

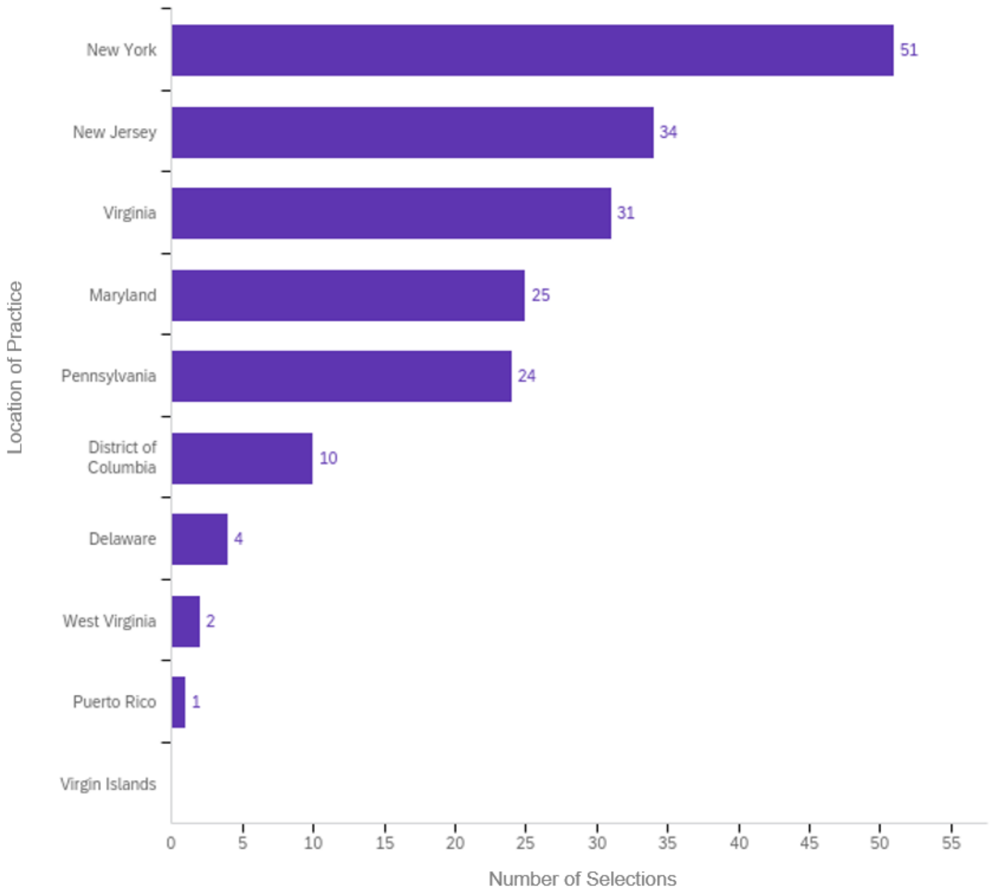


Figure 2. Distribution of Respondents' Clinical Practice Locations.

Respondents were also asked to indicate the size of their clinic or institution, and were able to select just one response. There was a mix of larger and smaller clinic sizes, with 44 out of 115 respondents (38%) who answered the question reporting a clinic size smaller than or equal to five clinicians, 39 (34%) reporting 6-15 clinicians, and the remaining 32 (28%) reporting a clinic size of 16 or more clinicians. This distribution is shown in Figure 3, below.

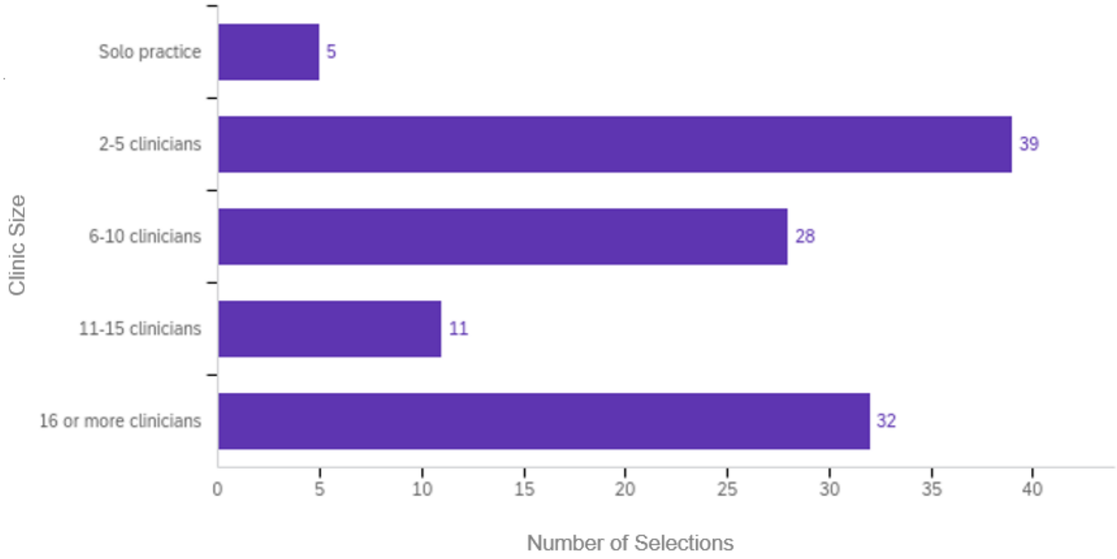


Figure 3. Distribution of Respondents' Clinical Practice Size by Number of Clinicians.

Next, respondents were asked to indicate their institution type, and were directed to select all institution types that applied to their practice. A total of 114 respondents answered this question, making 136 selections overall. As shown in Table 2 below, the greatest proportion of respondents indicated that their institution is Hospital/health system owned (51% of selections), while the second most common selection was Academic health center/faculty practice (37%). No respondents selected Federal (Military, Veterans Administration, Department of Defense) or Indian Health Service.

Table 2. Respondents' Practice Setting.

Practice Setting	*Percent of Selections*	*Number of Selections*
Clinician-owned solo or group practice	3.68%	5
Hospital/health system owned	51.47%	70
Health maintenance organization (e.g. Kaiser Permanente)	1.47%	2
Federally Qualified Health Center or similar	0.74%	1
Non-federal government clinic (e.g. state, county, city, public health clinic, etc.)	0.74%	1
Academic health center/faculty practice	36.76%	50
Federal (Military, Veterans Administration, Department of Defense)	0.00%	0
Rural Health Clinic	0.74%	1
Indian Health Service	0.00%	0
Laboratory	2.21%	3
Private business	0.00%	0
Other	2.21%	3
Total	100%	136

Additionally, there was a wide variety of clinical specialties offered at the respondents' clinics, as represented in Table 3 below. Respondents were directed to select all specialties offered at their clinic. In total, 115 respondents answered this question and made 385 selections, indicating that a number of respondents work at institutions offering services in several different clinical specialties. The most common specialty offered at respondents' institutions was pediatrics (n=59), making up 15% of all selections.

Table 3. Clinical Specialties Offered at Respondents' Clincal Practice Locations.

Clinical Specialty	*Percent of Selections*	*Number of Selections*
Adult	12.47%	48
Cancer	13.51%	52
Cardiovascular	7.79%	30
General	11.69%	45
Metabolic	9.61%	37
Neurogenetics	7.53%	29
Pediatric	15.32%	59
Prenatal	12.47%	48
Reproductive	7.27%	28
Other	2.34%	9
Total	100%	385

The ZIP codes provided by each respondent for their primary practice location were used to determine whether that respondent practices in an MUA. As shown in Figure 5 below, the majority of respondents (68%) reported a ZIP code that corresponded to a medically underserved area (MUA), as defined by HRSA (HRSA, 2021, n.d.). A total of 114 respondents answered this question, with one response per respondent.

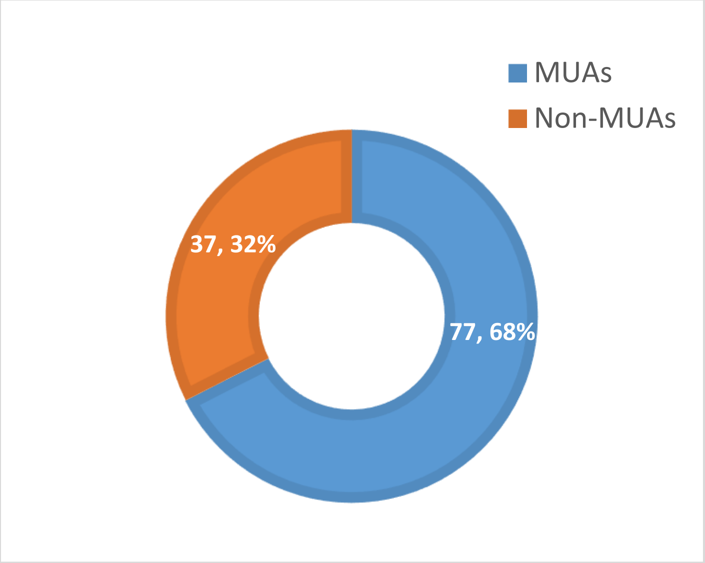


Figure 4. Respondents Practicing in Medically Underserved Areas (MUAs).

Each respondent was asked to estimate the percent of services they provided using different modalities, including in-person consultations, live video visits, phone consultations, and any other modality, both before and during the COVID-19 pandemic, as shown in Table 3 below. The estimates provided by each respondent were required to add up to 100%. On average, respondents reported seeing the majority of their patients (87.9%) through in-person consultations prior to the beginning of the COVID-19 public health emergency. The second most-utilized service delivery model was phone consultation (8.4%). This shifted during the COVID-19 public health emergency, during which the majority of patients were seen via telehealth modalities, with an average of 60.2% of patients seen via live video visit, and 23.0% via phone consultation. In-person consultations dropped to an average of 16.3% patients during this time.

Table 4. Average Percent of Patients Seen by Each Modality Before and During the COVID-19 Pandemic.

	Before COVID-19	During COVID-19
In-person consultations	87.9	16.3
Live video visit	3.1	60.2
Phone consultation	8.4	23.0
Store-and-forward	0.3	0.6
Other	0.4	5.0

3.4.2 Barriers to Providers Utilizing Telegenetics

Respondents reported a wide variety of barriers to utilizing telegenetics prior to the COVID-19 pandemic, as illustrated in Table 5 below, with a total of 376 selections made by 86 respondents. While respondents were directed to select the top three most significant barriers for healthcare providers utilizing telegenetics before the COVID-19 pandemic, they were able to select any number of responses, and each respondent made 4.37 selections, on average. The three most frequently reported barriers were lack of institutional support (n=45; 12% of selections), workflow and logistical issues (n=39; 10%), and inadequate funding, billing, and reimbursement (n=54; 14%).

Table 5 also indicates respondents' reported barriers to utilizing telegenetics during the COVID-19 pandemic. As previously described, respondents were directed to select their top three most significant barriers for healthcare providers utilizing telegenetics during the COVID-19 pandemic, but were able to select any number. Fewer total selections were made for barriers during the pandemic compared to barriers before the pandemic, with a total of 206 selections made by 86 respondents, for an average of 2.40 selections per respondent. The responses to this question indicated that workflow and logistical issues further increased during the pandemic (n=45; 22% of selections). Inadequate funding, billing, and reimbursement decreased while remaining the second most-selected barrier (n=26; 13%), and those indicating lack of institutional support decreased substantially during the pandemic (n=7; 3%).

Table 5. Barriers to Providers Utilizing Telegenetics Before and During the COVID-19 Pandemic.

Barriers to Providers Utilizing Telegenetics	*BEFORE COVID-19 Percent of Selections*	*BEFORE COVID-19 Number of Selections*	*DURING COVID-19 Percent of Selections*	*DURING COVID-19 Number of Selections*
Adequate patient access to existing in-person genetic services	4.26%	16	3.88%	8
Concerns about appropriate care coordination and follow up	3.19%	12	9.22%	19
Concerns about telegenetics limiting psychosocial care or education of patients	6.12%	23	7.28%	15
Inadequate funding, billing, and reimbursement	14.36%	54	12.62%	26
Issues with needed credentialing	3.19%	12	4.85%	10
Lack of appropriate technology	7.45%	28	9.71%	20
Lack of experience and training about telehealth	7.18%	27	6.80%	14
Lack of institutional support	11.97%	45	3.40%	7
Lack of necessary staff	2.66%	10	1.94%	4
Lack of patient interest or demand	6.91%	26	1.94%	4

Lack of provider interest	7.98%	30	0.49%	1
Lack of provider time	3.72%	14	0.97%	2
Licensure and legal issues	5.59%	21	7.77%	16
Trouble coordinating with other clinics where the patients would be located during telegenetics sessions	3.72%	14	3.40%	7
Workflow and logistical issues (sample collection, obtaining medical records)	10.37%	39	21.84%	45
Other	1.06%	4	2.91%	6
Does not apply	0.27%	1	0.97%	2
Total	100%	376	100%	206

Among providers practicing in non-medically underserved areas (non-MUAs), the most commonly reported barriers to providing services via telegenetics prior to the beginning of the COVID-19 pandemic were funding/billing/reimbursement (15.3% of selections), workflow/logistical issues (13.0%), and lack of institutional support (11.5%). In MUAs, the most commonly reported barriers were funding/billing/reimbursement (13.9%), lack of institutional support (12.4%), and lack of provider interest (9.6%). This information is summarized in Table 6, below.

Table 6. Barriers to Providers Utilizing Telegenetics Before the COVID-19 Pandemic in Medically Underserved Areas (MUAs) Compared to Non-MUAs.

Barriers to Providers Utilizing Telegenetics	*Percent of Selections from Respondents in MUAs*	*Percent of Selections from Respondents in Non-MUAs*
Adequate patient access to existing in-person genetic services	4.4%	4.6%
Concerns about appropriate care coordination and follow up	2.4%	4.6%
Concerns about telegenetics limiting psychosocial care or education of patients	5.2%	7.6%
Inadequate funding, billing, and reimbursement	13.9%	15.3%
Issues with needed credentialing	4.0%	1.5%
Lack of appropriate technology	6.4%	9.2%
Lack of experience and training about telehealth	6.0%	9.2%
Lack of institutional support	12.4%	11.5%
Lack of necessary staff	3.2%	1.5%
Lack of patient interest or demand	8.4%	4.6%
Lack of provider interest	9.6%	4.6%
Lack of provider time	3.6%	3.8%
Licensure and legal issues	5.2%	6.1%
Trouble coordinating with other clinics where the patients would be located during telegenetics sessions	4.8%	2.3%
Workflow and logistical issues (sample collection, obtaining medical records)	9.2%	13.0%
Other	1.2%	0.8%
Does not apply	0.4%	0.0%

After the beginning of the COVID-19 pandemic, the most commonly indicated barriers to providing services via telegenetics among providers practicing in non-MUAs were workflow/logistical issues (20.0% of selections), funding/billing/reimbursement (14.7%), and care coordination/follow-up (13.3%). Respondents practicing within medically underserved areas reported that their top barriers were workflow/logistical issues (22.9%), funding/billing/reimbursement (11.5%), and lack of appropriate technology (10.7%). This information is summarized in Table 7, below.

Table 7. Barriers to Providers Utilizing Telegenetics During the COVID-19 Pandemic in Medically Underserved Areas (MUAs) Compared to Non-MUAs.

Barriers to Providers Utilizing Telegenetics	*Percent of Selections from Respondents in MUAs*	*Percent of Selections from Respondents in Non-MUAs*
Adequate patient access to existing in-person genetic services	3.8%	4.0%
Concerns about appropriate care coordination and follow up	6.9%	13.3%
Concerns about telegenetics limiting psychosocial care or education of patients	7.6%	6.7%
Inadequate funding, billing, and reimbursement	11.5%	14.7%
Issues with needed credentialing	6.9%	1.3%
Lack of appropriate technology	10.7%	8.0%
Lack of experience and training about telehealth	5.3%	9.3%
Lack of institutional support	3.1%	4.0%
Lack of necessary staff	2.3%	1.3%
Lack of patient interest or demand	2.7%	1.5%
Lack of provider interest	0.0%	1.3%
Lack of provider time	0.0%	1.5%
Licensure and legal issues	9.2%	5.3%
Trouble coordinating with other clinics where the patients would be located during telegenetics sessions	3.8%	2.7%
Workflow and logistical issues (sample collection, obtaining medical records)	22.9%	20.0%
Other	3.1%	2.7%
Does not apply	0.0%	2.7%

3.4.3 Facilitators for Providers Utilizing Telegenetics

When asked to indicate facilitating factors for providing services via telegenetics prior to the COVID-19 pandemic, respondents were directed to select the top three most significant facilitators for healthcare providers utilizing telegenetics before the COVID-19 pandemic, but were able to select any number of responses. In response to this question, respondents made fewer selections overall, with 80 respondents making 146 selections, for an average of 1.83 selections per respondent. The most commonly reported facilitating factors were provider interest (n=19; 13% of selections), patient interest and demand (n=19; 13%), and institutional support (n=17; 12%). This information is summarized in Table 8, below.

Table 8 also illustrates respondents' selections of their most significant facilitating factors to using telegenetics during the COVID-19 pandemic. This question gathered a total of 297 selections from 80 respondents. Respondents were directed to select the top three most significant factors for healthcare providers utilizing telegenetics during the COVID-19 pandemic, but made an average of 3.71 selections per respondent. The three most commonly reported facilitating factors were institutional support (n=54; 18% of selections), provider interest (n=36; 12%), and patient interest and demand (n=55; 19%).

Table 8. Facilitators for Providers Utilizing Telegenetics Before and During the COVID-19 Pandemic.

Facilitators to Providers Utilizing Telegenetics	*BEFORE COVID-19 Percent of Selections*	*BEFORE COVID-19 Number of Selections*	*DURING COVID-19 Percent of Selections*	*DURING COVID-19 Number of Selections*
Institutional support	11.64%	17	18.18%	54
Available provider time	5.48%	8	5.72%	17
Provider interest	13.01%	19	12.12%	36
Patient interest and demand	13.01%	19	18.52%	55
Availability of other necessary staff	3.42%	5	3.37%	10
Solutions for workflow and logistical issues	8.90%	13	4.71%	14
Availability of appropriate technology	10.96%	16	11.78%	35
Adequate funding, billing, and reimbursement	5.48%	8	10.10%	30
Manageable licensure and legal issues	2.74%	4	3.37%	10
Solutions for care coordination and follow up	3.42%	5	1.35%	4
Available credentialing as needed	1.37%	2	1.35%	4
Lack of available in-person genetic services	3.42%	5	8.08%	24
Training or other assistance from NYMAC	5.48%	8	1.01%	3
Other	0.68%	1	0.34%	1
Does not apply	10.96%	16	0.00%	0
Total	Total	146	Total	297

Among respondents practicing in non-MUAs, the most commonly reported factors facilitating their use of telegenetics prior to the COVID-19 pandemic were patient interest/demand (17.6% of selections), institutional support (15.7%), and availability of technology (15.7%). Among respondents practicing in MUAs, the most common selections were does not apply (13.7%), provider interest (13.7%), and patient interest/demand (10.5%). These results are shown in Table 9, below.

Table 9. Facilitating Factors for Providers Utilizing Telegenetics Before the COVID-19 Pandemic in Medically Underserved Areas (MUAs) Compared to Non-MUAs.

Facilitators to Providers Utilizing Telegenetics	*Percent of Selections from Respondents in MUAs*	*Percent of Selections from Respondents in Non-MUAs*
Institutional support	9.5%	15.7%
Available provider time	6.3%	3.9%
Provider interest	13.7%	11.8%
Patient interest and demand	10.5%	17.6%
Availability of other necessary staff	2.1%	5.9%
Solutions for workflow and logistical issues	9.5%	7.8%
Availability of appropriate technology	8.4%	15.7%
Adequate funding, billing, and reimbursement	5.3%	5.9%
Manageable licensure and legal issues	4.2%	0.0%
Solutions for care coordination and follow up	4.2%	2.0%
Available credentialing as needed	2.1%	0.0%
Lack of available in-person genetic services	5.3%	0.0%
Training or other assistance from NYMAC	5.3%	5.9%
Other	0.0%	2.0%
Does not apply	13.7%	5.9%

Among respondents practicing in non-MUAs, the most commonly selected facilitating factors for providing services via telegenetics during the COVID-19 pandemic were institutional support (18.6% of selections), patient interest/demand (17.6%), availability of technology (12.7%), and provider interest (12.7%). Among respondents practicing in MUAs, the most commonly selected facilitating factors were patient interest/demand (19.0%), institutional support (18.0%), and provider interest (12.0%). This information is summarized in Table 10, below.

Table 10. Facilitating Factors for Providers Utilizing Telegenetics During the COVID-19 Pandemic in Medically Underserved Areas (MUAs) Compared to Non-MUAs.

Facilitators to Providers Utilizing Telegenetics	*Percent of Selections from Respondents in MUAs*	*Percent of Selections from Respondents in Non-MUAs*
Institutional support	18.0%	18.6%
Available provider time	5.5%	5.9%
Provider interest	12.0%	12.7%
Patient interest and demand	19.0%	17.6%
Availability of other necessary staff	3.5%	2.9%
Solutions for workflow and logistical issues	4.5%	5.9%
Availability of appropriate technology	11.0%	12.7%
Adequate funding, billing, and reimbursement	11.5%	7.8%
Manageable licensure and legal issues	3.5%	2.9 %
Solutions for care coordination and follow up	1.5%	1.0%
Available credentialing as needed	1.0%	2.0%
Lack of available in-person genetic services	8.5%	6.9%
Training or other assistance from NYMAC	0.5%	2.0%
Other	0.0%	1.0%
Does not apply	0.0%	0.0%

3.4.4 Resources Utilized and Resources Needed to Facilitate the Use of Telegenetics

Figure 5, below, shows which NYMAC and/or RGN resources respondents reported that they or others in their clinic had used to support their telegenetics services. Out of 99 total selections, 53 (53% of selections) indicated they did not use any NYMAC or RGN resources. The most frequently reported resources utilized by respondents were Virtual or in-person telegenetics training (n=18; 18%) and NYMAC Telegenetics Community of Practice conference calls and/or webinars (n=13; 13%). A total of 77 respondents answered this question.

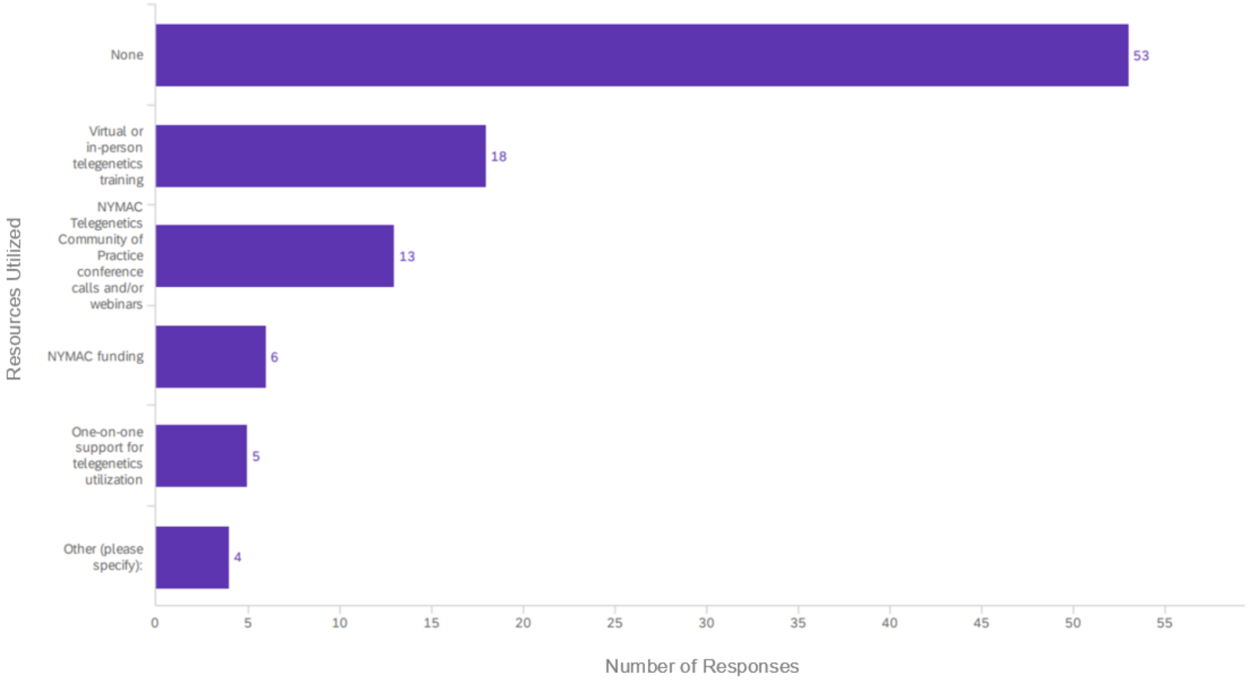


Figure 5. NYMAC/RGN Support Resources Utilized at Respondents' Clinics.

Figure 6, below, shows resources and support services that respondents indicated may be helpful to them, with a total of 195 selections made by 80 respondents. The most frequently desired resources were assistance with billing and reimbursement (n=45; 23% of selections), assistance with policy issues including licensure, telehealth laws, and consent (n=43; 22%), and resources for patients to use telegenetics (n=35; 18%).

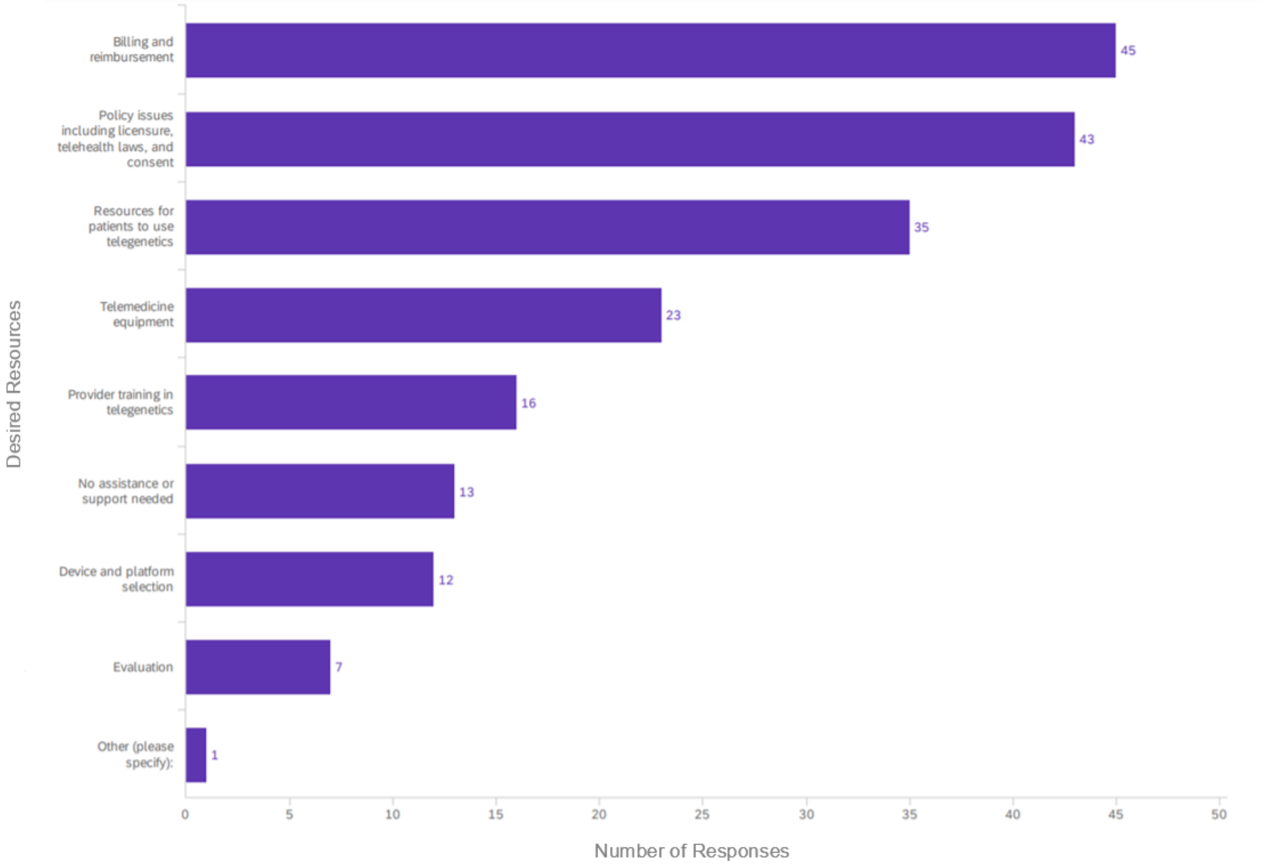


Figure 6. Respondents' Desired Telegenetics Support and Resources.

When asked, the majority of respondents (n=48; 59.26%) indicated that their clinic planned to continue offering services via alternative models after the COVID-19 pandemic subsides. The minority of respondents (n=6; 7.41%) indicated that they did not plan to continue offering alternative models. The remaining 33.33% of respondents (n=27) were unsure. A total of 81 respondents answered this question, with one response for each respondent. This information is illustrated in Figure 7, below.

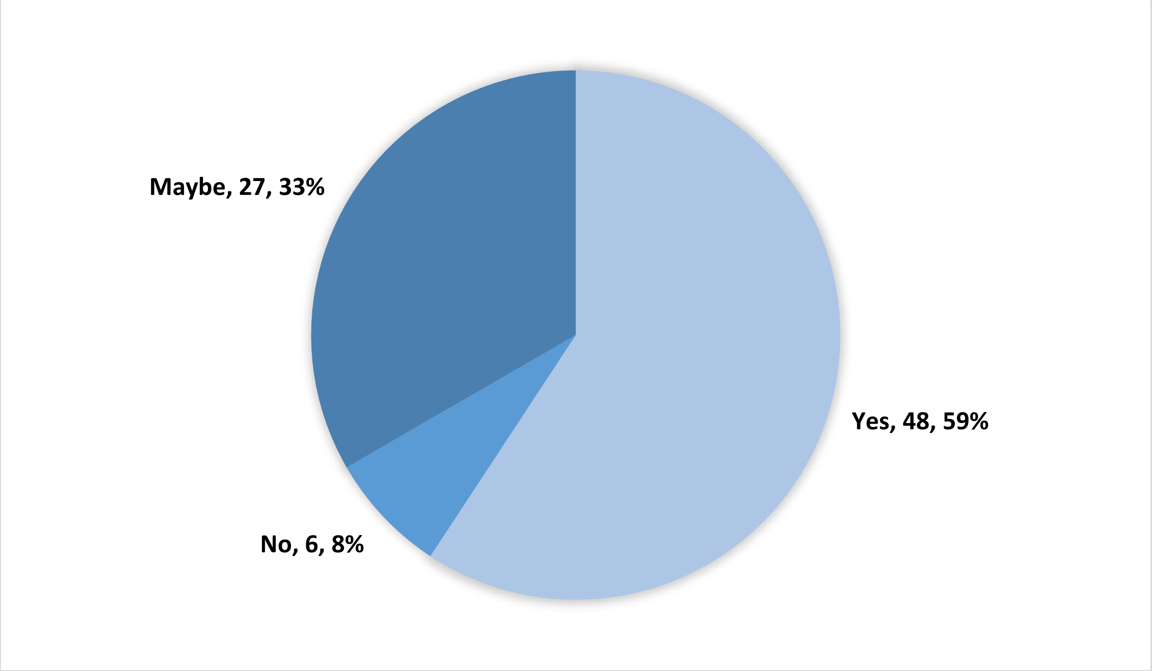


Figure 7. Respondents' Plans to Continue Offering Services via Telehealth Modalities.

3.5 Discussion

3.5.1 Barriers to Providers Utilizing Telegenetics

Prior to the beginning of the COVID-19 pandemic, several barriers to providing genetic services via telehealth were already described in the literature. These barriers included professional licensure requirements, issues with billing or reimbursement, concerns about adequately providing psychosocial care, a lack of resources and technical equipment, technical issues, lack of supporting regulations, a lack of professional support, a lack of need seen for telegenetics services, difficulty with coordination of care, and data security concerns (Terry et al., 2019; Vrecar et al., 2017; Zierhut et al., 2018). This survey revealed many of the same barriers faced by providers within the NYMAC region prior to the COVID-19 pandemic, with issues related to a lack of institutional support (n=45; 12% of selections), workflow and logistical issues (n=39; 10%), and inadequate funding, billing, and reimbursement (n=54; 14%) most commonly reported.

While there is still limited research about barriers to providing telehealth services during the COVID-19 pandemic, one study suggests that existing telehealth infrastructure at the beginning of the pandemic was inadequate to address the high demand for telehealth services at that time (Hong et al., 2020). Other reports from clinics transitioning to telehealth during the pandemic described difficulties such as inadequate internet access, patients' distractions when attending telehealth sessions from their homes, physical exams being limited by video capabilities, workflow changes, and privacy concerns for patients discussing sensitive topics in the presence of family members or partners (Aziz et al., 2020; Pereira et al., 2020). Of these concerns, the primary concern indicated by respondents to our survey during the pandemic was concern for workflow and logistical issues. While workflow and logistical issues accounted for 10% of reported barriers prior to the pandemic, this proportion increased to 22% (n=45) during the COVID-19 pandemic, becoming the most-often reported barrier in this time period. Although examples of workflow and logistical issues were given in the survey (sample collection, obtaining medical records), it is possible that respondents' interpretation of this factor may vary.

Inadequate funding, billing, and reimbursement issues remained the second-most reported barrier at 13% of selections (n=26), but there was a substantial change in reported lack of institutional support during the pandemic. While a lack of institutional support accounted for 12% of reported barriers prior to the pandemic, this proportion decreased to 3% (n=7) during the pandemic, reflecting institutions' efforts to transition to telehealth to avoid COVID-19 transmission within their institutions while still providing needed care to patients. Indeed, institutional support became the second-most frequently reported facilitating factor for providing telegenetics services during the COVID-19 pandemic, at 18% of selections (n=54). These trends have been reflected in reports of hospital spending during this time. In the context of projected losses of up to $323.1 billion in 2020, a 19.5% reduction in inpatient admissions and a $34.5% reduction in the number of outpatients seen in June 2020, and an increased number of cyber attacks in 2020, hospitals reported prioritizing technology and IT upgrades in their budgets over recruitment and hiring of new healthcare professionals in October of 2020 (AHA, 2020; HIMMS, 2021).

In addition to describing overall barriers to providing genetics services via telehealth before and during the COVID-19 pandemic, this study sought to understand any differences in barriers for medically underserved areas (MUAs). Stratifying reported barriers by providers practicing within MUAs vs. Non-MUAs revealed that inadequate funding/billing/reimbursement (13.9% of selections in MUAs; 15.3% in Non-MUAs) and lack of institutional support (12.4% in MUAs; 11.5% in Non-MUAs) were among the top three most commonly reported barriers for both groups prior to the COVID-19 pandemic. However, lack of provider interest was more commonly reported as a barrier by providers in MUAs (9.6% of selections) compared to Non-MUAs (4.6%), while workflow/logistical issues were less commonly reported in MUAs (9.2%) than in Non-MUAs

(13.0%). Because rural hospitals were more likely to have existing telehealth capabilities than urban hospitals prior to the pandemic (Puro & Feyereisen, 2020), it may be that rural hospitals in MUAs more often had existing infrastructure with an established workflow for telehealth appointments, such that provider interest played a larger role in determining to what extent telehealth services would be used.

As in the whole group, barriers reported during the COVID-19 pandemic also shifted in the MUA and Non-MUA stratified groups. In both groups, workflow/logistical issues became more prominent (22.9% of selections in MUAs; 20.0% in Non-MUAs), while inadequate funding/billing/reimbursement remained a common concern (11.5% in MUAs; 14.7% in Non-MUAs). However, during this time period, lack of appropriate technology became a more frequently reported concern among providers in MUAs (10.7%) compared to Non-MUAs (8.0%). This appears to contradict prior research suggesting that rural hospitals were more likely to have existing telehealth infrastructure prior to the pandemic (Puro & Feyereisen, 2020). However, Puro and Feyereisen did not distinguish between telehealth taking place directly to patients' homes and telehealth services linking one clinical location to another (hub-and-spoke). Therefore, it is possible that hospitals with existing hub-and-spoke telehealth programs still encountered difficulty in obtaining appropriate technology to provide telehealth services directly to patients' homes during the COVID-19 pandemic. Additionally, concerns regarding care coordination/follow-up were less commonly reported among providers in MUAs (6.9%) compared to Non-MUAs (13.3%). If hospitals within MUAs did more often have existing telehealth capabilities prior to the pandemic, even if primarily hub-and-spoke rather than directly to patients' homes, these hospitals may also have had existing protocols to coordinate care and follow-up services for patients.

It is notable that inadequate funding/billing/reimbursement remained among the top three most commonly reported barriers both before and during the COVID-19 pandemic, both in MUAs and Non-MUAs. Indeed, genetic counselors are not recognized as healthcare providers by CMS, and as a result must bill for services provided to Medicare patients "incident to" a physician (NSGC, 2021), both prior to and during the pandemic. Some private payers also do not cover the cost of services provided by genetic counselors, in part because they lack CMS recognition (Doyle et al., 2015). Despite changes to billing policies for the Centers for Medicare & Medicaid Services (CMS) on March 17, 2020 that would allow billing to CMS covered services that are provided via telehealth (Gausvik & Jabbarpour, 2021), a survey of genetic counselors in New York found no significant difference in how genetic counselors billed for services during the COVID-19 pandemic (Bergstrom, Brander, Breen, & Naik, 2021). In addition, by April 1, approximately 40% of primary care offices still did not have the ability to provide services via video conferencing, and only 34% of primary care providers reported that their clinics had enough money to stay open for the next four weeks. Because of these financial losses, a June estimate predicted that 20,000 primary care doctors would lose their jobs, resulting in a shortage of primary care providers in 287 additional U.S. counties, or 25% more counties experiencing primary care shortages compared to before the COVID-19 pandemic (Gausvik & Jabbarpour, 2021; PCC, 2020). While these estimates are specific to primary care practices rather than genetics practices, they do provide some insight into the financial difficulties experienced by many hospitals and clinics during the COVID-19 pandemic, in part because of the difficulty that some hospitals and clinics experienced in getting the appropriate technology to transition to telehealth.

These results do not address barriers to patients accessing telehealth genetics services. Indeed, additional research is necessary to clarify access barriers for patients during the COVID-

19 pandemic, and to assist in the development of resources to facilitate access to healthcare services. Publications prior to the COVID-19 pandemic have shown that patients living within MUAs may experience problems with broadband access, which can limit their ability to participate in telehealth video conferencing. Indeed, 24 million people in the United States live in areas without broadband access, including 19 million rural residents and 1.4 million on Tribal lands (Bauerly et al., 2019). Patients lacking broadband access may need to receive services via phone consultations or written communication through a patient portal for an electronic health record system. However, these telephone and electronic communication systems are not reimbursed at the same level as video conferencing by CMS (Woodall, Ramage, LaBruyere, McLean, & Tak, 2021). This loss in revenue may lead to financial hardship among clinics and institutions whose patient base includes a larger proportion of medically underserved patients. To address the problem of patient broadband access, a perspectives article from a Michigan hospital system suggested allowing patients to attend their telehealth appointments from their parked car near an Internet hotspot or within an affiliated clinic, while a feasibility study in the state of Virginia suggested using the technology and broadband access available within local public libraries to facilitate patient access to telehealth appointments (DeGuzman et al., 2020; Hirko et al., 2020). Additionally, an article written by researchers from the CDC’s Public Health Law Program describes public policies that promote broadband expansion, such as laws providing funding, encouraging private investment, facilitating public-private partnerships, and placing broadband infrastructure at the same time as other infrastructure is being placed (Bauerly et al., 2019).

3.5.2 Facilitators for Providers Utilizing Telegenetics

Similarly, there has been a shift in motivating or facilitating factors for providing services via telegenetics, before compared to during the COVID-19 pandemic. Generally, before the pandemic, it was understood there were too few genetics providers for the existing demand for genetic services (Cooksey et al., 2005; Cosgrove et al., 2020; Hoskovec et al., 2018; Maiese et al., 2019). Telegenetics was suggested as a way to reduce barriers to genetics services, and in some clinics, telegenetics programs reported shorter wait times for new appointments (Hilgart et al., 2012; Terry et al., 2019). In addition to this understood usefulness of telegenetics programs for increasing access, an additional facilitating factor was provider interest. Indeed, one study found that 92% of genetic counselors who didn't provide services via telegenetics were "at least slightly interested" in telegenetics (Zierhut et al., 2018). The results of this survey showed similar facilitating factors, with provider interest reported as the most common factor facilitating the use of telegenetics prior to COVID-19 (n=19; 13% of selections), along with patient interest and demand (n=19; 13%).

During the pandemic, not only did the proportion of providers offering services via telegenetics change; the facilitating factors reported by these providers also changed. While there are still limited reports, some institutions have reported that providers quickly became familiar with telehealth platforms and transitioned to providing services via telehealth; out-of-state licensure restrictions were relaxed; the telehealth format was helpful for patients who worked from home or had additional childcare responsibilities; and as many as 50% of patients may prefer to receive services via telehealth, regardless of the pandemic (Aziz et al., 2020; Pereira et al., 2020). Respondents to our survey reported similar facilitating factors: the most frequently selected facilitating factors were patient interest and demand (n=55; 19%) and institutional support (n=54;

18%), reflecting the same factors of patient interest and institutions' rapid transition to telehealth reported by other hospitals during the pandemic.

As with barriers, this study sought to understand differences in factors that facilitated the use of telehealth before and during the COVID-19 pandemic in MUAs compared to Non-MUAs. In both MUAs and Non-MUAs, patient interest and demand (10.5% of selections in MUAs; 17.6% in Non-MUAs) ranked among the top three most commonly reported facilitators prior to the pandemic. However, in MUAs, more common selections included does not apply (13.7%), indicating no factors facilitating the use of telehealth prior to the pandemic, and provider interest (13.7%). Again, this appears to possibly contradict Puro and Feyereisen, whose research suggests that prior to the pandemic, rural hospitals were more likely to have existing telehealth infrastructure (Puro & Feyereisen, 2020). These results also appear to contradict MUA providers' previous responses describing the lack of provider interest as one of the most commonly reported barriers. However, it may be that provider interest or lack of interest was a stronger determinant of whether an MUA clinic offered telegenetics services prior to the pandemic, and that other factors prevented the use of telehealth services by genetics professionals despite the availability of telehealth equipment at some MUA clinics. By comparison, in Non-MUAs, respondents commonly indicated institutional support (15.7%) and availability of technology (15.7%) as facilitating factors. It is not clear why respondents were more likely to report the availability of technology as a facilitating factor prior to the pandemic, given the findings from Puro and Feyereisen previously discussed. However, it may be that at clinics or institutions with existing telehealth equipment, individual departments' access to telehealth equipment varies, and institutional support may play a role in whether genetics departments have access to the equipment.

After the beginning of the COVID-19 pandemic, both MUAs and Non-MUAs most commonly reported institutional support (18.0% in MUAs; 18.6% in Non-MUAs), patient interest and demand (19.0% in MUAs; 17.6% in Non-MUAs), and provider interest (12.0% in MUAs; 12.7% in Non-MUAs) as factors facilitating their use of telehealth, though respondents from Non-MUAs did commonly report availability of technology (12.7%) as a facilitating factor as well. As previously described, these factors of patient interest/demand and institutional support reflect published experiences of other hospitals in transitioning genetics services to a telehealth format during the COVID-19 pandemic (Aziz et al., 2020; Pereira et al., 2020).

3.5.3 Resources Utilized and Resources Needed to Facilitate the Use of Telegenetics

In addition to identifying barriers and facilitating factors to providing telegenetics services, this study sought to identify the resources that may be necessary for providers, clinics, and broader institutions to continue offering genetics services via telehealth following the close of the pandemic. This may be particularly important given the substantial degree of uncertainty expressed by respondents about whether they would continue offering services via telehealth; while nearly 60% of respondents indicated that they would continue to use telehealth and 7% would not, 33% of respondents were unsure. Though 53 respondents (53% of selections, or 69% of the providers who answered the question) indicated that they did not use any NYMAC or RGN resources to support their use of telehealth, respondents indicated a number of resources that would be helpful to them or to their clinics to continue providing telegenetics services. The most commonly indicated support resources were help with billing and reimbursement (n=45; 23% of selections), policy issues including licensure, telehealth laws, and consent (n=43; 22%) and resources for patients to use telegenetics (n=35; 18%). A smaller proportion of selections indicated no assistance or support needed (n=13; 7%). This information will be useful to NYMAC and other RGNs as they work to develop support resources for telegenetics providers.

3.5.4 Project Limitations

The survey was distributed in July, 2020, to gather information about genetics providers' initial perceptions about the transition to telehealth during the COVID-19 pandemic. While the survey does provide a snapshot into providers' experiences at this time point, the early distribution of the survey does limit its generalizability to later time periods.

This survey aimed to gather information at the clinic level, to understand differences in how different genetics clinics are adapting to COVID-19. Because of this focus, one of the first questions in the survey is a free-entry text box for respondents to enter the name of their clinic. However, many respondents instead listed the name of a broader hospital system or institution, so that we could not distinguish whether each data point reflected separate individual clinics, or whether there were multiple responses from the same clinics. In addition, because the survey was de-identified to protect respondents' privacy, IP addresses are not attached to the responses to indicate whether there may be multiple responses from the same participant. Therefore, one limitation of this survey is the potential for duplicate data points that cannot be removed.

Additionally, while the survey received 169 responses in total, 91 respondents (54%) completed the entire survey, with four respondents (2%) "finishing" the survey by being sent to the end, upon indicating that they did not practice within the region. An additional 49 respondents (29%) quit the survey when asked for their ZIP code, even though these respondents had previously indicated that they practiced in at least one NYMAC state or territory. In addition to collecting ZIP codes as part of the data that NYMAC reports to the National Coordinating Center for the Regional

Genetics Networks (NCC), the ZIP codes were also desired to allow stratification of the data into clinics providing services within MUAs vs. clinics that are not located within MUAs. It may be that respondents declined to provide their ZIP code because they were unwilling or uncomfortable with providing this information, or perhaps that they did not have their clinic’s ZIP code available to them when they were taking the survey. Because of the importance of this information for NYMAC and the NCC, future studies may consider possible reasons for this drop-off, to avoid incorporating any self-selection bias into their studies.

A number of respondents (n=29, 17%) completed about half the questions in the survey. A close look at the data spreadsheets indicates that these respondents were not following survey logic that directed them to half of the questions, but rather that they closed the survey window prior to completion. This decreased number of responses limits the statistical calculations that can be performed using the data from this survey, and in addition to the concerns about possible duplicates in the data, lowers its potential generalizability. To increase the sample size as much as possible, partial answers were still included in the analysis, and is the reason why some figures have a different number of total responses than others. In addition, it was not possible to calculate a response rate for the survey. Because the survey was distributed using listservs with an uncertain number of recipients and possible overlap of recipients belonging to more than one listserv, the total number of people who received an invitation to the survey is unknown.

3.5.5 Future Directions

This essay has focused on analyzing and interpreting a narrow subset of questions on the NYMAC Telegenetics Survey. Therefore, future studies analyzing the remainder of the survey questions, which include questions such as what providers perceive to be barriers and facilitators to their patients accessing telegenetics services, will be important to provide additional information about the use of telegenetics during this time period. Additionally, this study does not directly assess barriers and facilitators for patients. Future studies examining these factors from patients' perspectives may provide additional information to organizations like NYMAC and other regional genetics networks about further ways to improve access to genetics services through telehealth.

As previously discussed, this study is limited to describing the use of telegenetics in the summer of 2020. However, additional studies examining the evolution of provider perspectives and telegenetics use at later time points will be informative. Toward this end, interviews of genetics providers were conducted in April and May of 2021, as described in Chapter 4.0.

3.6 Conclusions

Survey respondents indicated a number of barriers and facilitators to their use of telegenetics before and during the COVID-19 pandemic. Institutional support substantially increased during this time, facilitating the transition to telehealth along with provider and patient interest. Workflow issues increased, possibly due to remote work disrupting typical logistical processes. Respondents commonly reported problems with funding, billing, and reimbursement, both before and during the pandemic. It is not surprising, then, that when asked about necessary resources, respondents most commonly indicated that they could benefit from help with billing and reimbursement. This information will be helpful for NYMAC and other organizations as they work to support the use of telegenetics in the future. This support will be particularly important, given that while nearly 60% of respondents indicated that they plan to continue offering services via telegenetics after the pandemic, as much as 33% were uncertain. This study is limited in its size, but may serve as an insight into challenges faced during the COVID-19 pandemic, and as a starting point for additional research regarding barriers and facilitators going forward.

4.0 Manuscript

4.1 Background

Prior to the COVID-19 pandemic, the literature described a number of barriers to accessing genetics services. A recent report from the GAO described increasing demand for genetics services, coupled with a geographic maldistribution of genetics professionals (Cosgrove et al., 2020). An earlier workforce survey had described a "critical" shortage of medical geneticists as well as problems with geographic distribution, with 17 states lacking the minimum number of medical geneticists required to serve the population (Cooksey et al., 2005). These issues of geographic distribution also appear to affect the New York-Mid Atlantic Caribbean (NYMAC) region, in which the number of genetics clinics varies a great deal from one state or territory to another, and not always in connection with population size (ACMG, 2021). A recent study also described an inadequate number of genetic counselors, but calculated that the supply of genetic counselors and the demand for genetics services would equalize around 2024-2030 (Hoskovec et al., 2018). Wait time poses another barrier to accessing genetics services, as a survey showed that 62% of geneticists had a wait time of at least one month for non-emergency, new consults (Maiese et al., 2019).

Telehealth, or "the use of electronic information and telecommunication technologies to support long-distance clinical health care, patient and professional health-related education, public health, and health administration," as defined by HRSA (HRSA, 2020) has been described as a way to reduce barriers to accessing genetics services (Hilgart et al., 2012). This can involve video conferencing, sometimes using a hub-and-spoke (originating site/distant site) model, in which the patient presents to a satellite clinic to video conference with the provider at another clinical site; telephone consults; and store-and-forward, or the not-in-real-time, electronic sending and receiving of patient information from one clinician to another for clinical recommendations. In a 2016 survey of genetics providers within the NYMAC region providing services via telehealth video conferencing, 56% of respondents reported a wait time of less than two weeks, and 50% reported seeing patients greater than 200 miles away (Terry et al., 2019). In studies assessing providers' use of telehealth, a 2015 survey found that only 20.8% of genetic counselors and 15.8% of geneticists had previously provided services via telehealth (Maiese et al., 2019), while a 2016 survey of genetic counselors suggested that the proportion may be as high as 68.3% of genetic counselors (Zierhut et al., 2018). In this second survey, among genetic counselors who had not previously provided services via telehealth, 92% were "at least slightly interested" in using telehealth in the future (Zierhut et al., 2018). Furthermore, studies assessing patient reception to telehealth services have shown that the majority of patients value provider expertise more highly than in-person services (McDonald et al., 2014), and patients receiving genetic counseling via telehealth showed no significant difference in their level of understanding compared to in-person services, they expressed satisfaction with the service, and had significant reductions in depression after counseling, though 32% said they would have preferred in-person counseling (Solomons et al., 2018).

Despite the access barriers which may be reduced through telehealth and the facilitating factors encouraging its use, a number of barriers restrict the use of telehealth. These barriers include problems with billing and reimbursement, licensure and credentialling, inadequate technical equipment, logistical issues such as coordinating with providers at the satellite location, concerns about addressing psychosocial factors, and technology difficulties including patient technology literacy, patients' access to high-speed broadband, and appropriate technology (DeGuzman et al., 2020; Shah et al., 2009; Terry et al., 2019; Zierhut et al., 2018).

As one of the RGNs funded by HRSA's Maternal and Child Health Bureau, the NYMAC RGN works towards the NCC's mission "to improve access to quality genetic services for underserved populations" (NCC, 2020a). NYMAC also works to "Facilitate the use of telehealth in genetics," and serves the states and territories of Delaware, Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, the U.S. Virgin Islands, Virginia, Washington D.C., and West Virginia. In order to help increase access to genetics services for patients living within the region through promoting telehealth, NYMAC has partnered with the Western States Regional Genetics Network (WSRGN) to provide trainings to genetics providers within the region (Terry, May 25, 2021; WSRGN, 2017), and also provides other support including grants and technical assistance (NYMAC, n.d.-b).

In the context of these long-standing benefits, facilitating factors, and barriers to telegenetics, existing efforts to facilitate the use of telegenetics, and overall access issues for patients seeking genetics services, the SARS-CoV-2 virus, or COVID-19, emerged in December, 2019, rapidly spreading across the globe. On March 11, 2020, the World Health Organization declared a pandemic, and travel restrictions, city lockdowns, and social distancing guidelines soon followed in cities and states across the United States. Across specialties, healthcare providers and their institutions rapidly transitioned to providing services via telehealth, despite inadequate existing infrastructure (Hong et al., 2020). Some genetics clinics that rapidly published their experiences described shifting barriers and benefits: some patients lacked the necessary Internet access, experienced a lack of privacy during difficult decision making, or struggled with remote interpreter services, while others felt less anxious, were able to attend with support persons, or didn't have to take time off work or find childcare (Aziz et al., 2020; Pereira et al., 2020).

A great deal has changed since the beginning of the COVID-19 pandemic, and there is significant information to be learned about genetics providers' experiences transitioning to telehealth during the pandemic, the challenges they faced, and what needs are still unmet. This study, conducted in partnership with NYMAC, aims to gain a richer understanding of these experiences. The findings of this study will inform future efforts from NYMAC, other regional genetics networks, public health organizations, hospitals, and policymakers, as they work to support providers and patients to increase access to genetics services.

This study aims to:

AIM 1: Use the results of the online survey to create a list of interview questions to discuss with genetics providers. Analyze interview transcripts, using qualitative thematic analysis, to assess the following:

- Barriers and facilitators to the provision of telegenetics during the COVID-19 public health emergency
- The perceived value of and demand for telegenetics services during the public health emergency

AIM 2: Use the results of the survey and thematic analysis to determine what resources or policy changes may be necessary in order to continue providing such services after the pandemic.

4.2 Methods

Prior to any research methods being conducted, the study methods were submitted to the University of Pittsburgh Institutional Review Board (IRB) for approval. Research participants were recruited and interviewed, and the interview transcripts were analyzed using thematic analysis, as described below.

4.2.1 Ethical Considerations

The protocol for the survey portion of this study, along with the initial interview recruitment protocol, was approved by the University of Pittsburgh IRB as an exempt study on June 24, 2020. An updated IRB submission with new recruitment protocol through the NYMAC Telegenetics Community of Practice (TCOP), along with the introductory script for the interviews and interview questions, was approved on March 30, 2021, still as an exempt study. The IRB approval letters are attached in Appendix A.

4.2.2 Recruitment

Recruitment was initially attempted through the NYMAC Telegenetics Survey, which was distributed to genetics professionals within the NYMAC region through several listservs in July 2020, including: NYMAC directory and email lists; the NYMAC Telegenetics Community of Practice (TCOP); the National Society of Genetic Counselors; and the State Genetics Provider Groups for New York, Maryland (including Washington, D.C.), Virginia, Pennsylvania, and New Jersey. In the NYMAC Telegenetics Survey, participants were asked if they would like to receive additional information from NYMAC about on-on-one support and future telegenetics trainings, and/or if they would be willing to participate in an interview to assess telegenetics utilization. Interested respondents were directed to click a link leading them to a separate survey in which they could indicate which communications they would like to receive and submit their email address, to keep this potentially identifiable information separate from their responses to the NYMAC Telegenetics Survey. However, this secondary survey yielded no volunteers for the interviews.

As a secondary method of recruitment, individual members of the NYMAC TCOP were selected by TCOP leadership and invited to participate in the interviews. TCOP leadership contacted potential interviewees via email, using the IRB approved introductory text (Appendix C.1). TCOP members who agreed to participate in an interview were then contacted via email to schedule an interview time.

4.2.3 Interviews

An interview script (Appendix C.2) was developed to elicit provider perspectives on barriers to the provision of telegenetics during the COVID-19 pandemic, the perceived value and demand for telegenetics during this time period, and the resources or policy changes that may be necessary to continue offering these services after the close of the pandemic. In addition to these interview questions, appropriate follow-up questions were asked as needed. Two pilot interviews were conducted to finalize interview questions and interview flow, as well as to establish an expected interview length of approximately 30 minutes. These pilot interviews were excluded from data analysis.

Five interviews were conducted, with the goal of establishing a richer understanding of different perspectives of telegenetics during the COVID-19 pandemic and informing the findings of the NYMAC Telegenetics Survey project. The interviews were audio- and video-recorded via Zoom and recordings were stored in a secure cloud drive. The average interview time was approximately 36 minutes.

4.2.4 Thematic Analysis

Each interview was conducted and recorded via Zoom, as described above. The interview recordings were automatically encrypted and transferred to Panopto, where it was automatically transcribed. Interview transcripts were de-identified and stored in a secure cloud drive. Each interview was re-played to manually correct errors in the computer-created transcription.

After the transcription process, the interview transcripts were analyzed using thematic analysis. No themes were pre-defined. Instead, an inductive, data-driven approach was used to identify codes in each transcript. One codebook created and shared across all five interview transcripts (Braun & Clarke, 2006). The lead researcher coded all transcripts and a second member of the research team performed an audit of the codebook and the first three coded interview transcripts. This audit process resulted in additional codes being identified in the interview transcripts and other codes being modified until consensus was reached. Following the coding of the interview transcripts, the shared codebook was used to identify themes across interviews, with each theme subsequently checked against the original transcripts in an iterative process. The resulting themes described meanings within the interview transcripts at the explicit, or semantic, level (Braun & Clarke, 2006).

Excerpts from the interview transcripts were de-identified prior to inclusion in this manuscript. As part of this de-identifying process, each participant is referred to with singular "they" pronouns to protect the identity of the participants.

4.3 Results

Out of 169 respondents to the NYMAC Telegenetics Survey, zero providers volunteered to participate in an interview. As a secondary method of recruitment, the NYMAC Telegenetics Community of Practice (TCOP) invited individual members of the TCOP directly. A total of five interviews were conducted with members of the TCOP who agreed to participate. Of the five providers interviewed, two practice within the state of Virginia, two in New York, and one in Pennsylvania. Four of the providers are genetic counselors, and one is a medical geneticist. The providers had a range of 8 to 23.5 years of practice, with a median of 11 years. While two of the providers described working with medically underserved patients “to a small extent,” the other three described more substantial work with MUPs. The providers interviewed described a variety of practice settings, including private independent practice, working at for-profit institutions, and working at university-affiliated hospitals. These providers’ states, practice setting, level of experience, and work with MUPs inform their experiences, and provided a rich variety of perspectives.

Thematic analysis of the interview transcripts established six themes and two sub-themes, as shown in Table 3. These themes are Benefits of Telehealth, Limitations of Telehealth, External Factors, Evolving Models, Provider Adaptation, and Institutional Engagement. The theme of Limitations of Telehealth also includes two subthemes: Social Factors and Patient Technology.

Table 11. Themes and Subthemes Identified in Provider Interviews.

Theme	Subthemes
Benefits of Telehealth	
Limitations of Telehealth	Social Factors Patient Technology
External Factors	
Evolving Models	
Provider Adaptation	
Institutional Engagement	

4.3.1 Benefits of Telehealth

Throughout the interviews, participants described the benefits of providing genetics services via telehealth, as they experienced it during the COVID-19 pandemic. Though each participant gave their own perspective as a genetics provider, they offered thoughts about how the use of telehealth impacted not only themselves, but also their patients, the institutions they work for, and referring providers. For example, one participant explained how the use of telehealth could alleviate travel time for both provider and patient:

> *Within the institution, just because of the large geography that's associated with it, just to ease of use, if patients could - even if they were 15 minutes to an hour away, if there were a more local [institution] based location that they could go to, and use more of a telehealth, where I could still be here physically in [city] instead of traveling an hour to that location, whether it be north, south, east or west*. (Participant 2)

Another participant echoed the same, adding that not only could the use of telehealth alleviate long travel time for patients, it could also allow more patients to access the services:

> *There were quite a few patients that were driving an hour plus to the appointment, so that was something that drew me to it, and just knowing that it would expand who could access the service.* (Participant 3)

The same participant described how the increased availability of telehealth at their institution during the COVID-19 pandemic impacted referring providers from other institutions:

> *It opened up more referral streams from providers that were previously hesitant to refer because they knew their patients would have to drive a significant distance. So, I would say that referring providers responded positively because it improved access for their patients*. (Participant 3)

In addition to increased access to genetics services because of reduced travel time, participants described other factors that improved the ease of access for their patients. For example, one participant noted that offering telehealth appointments resulted in noticeable time savings, even for patients who live much closer to the clinical site:

> *I'm in the suburbs - but yes, even then, people saying - well, it saves me driving there and parking. [. . .] Let's say you're 20 minutes from where I might normally be. You've cut down on about an hour, at least, of time. And during COVID, people were really happy not to be in person*. (Participant 4)

The same participant explained that this ease of access also benefited their private practice, because it became a selling point for potential clients:

> *It seemed like the best – one of the ways to try to make myself competitive was to make it easy for the patient. So that was what I was trying to do*. (Participant 4)

Another participant described how these factors benefiting patients – reduced travel, lower anxiety, and general ease of access – also combine to benefit both provider and institution by reducing the number of patients who do not show up to their appointments, and ultimately increasing reimbursement in the genetics department despite the COVID-19 pandemic:

> *Our reimbursement for our department has actually increased since the pandemic. And it's because our no-show rate is down, because people are much more likely to come for a virtual appointment than they are to a downtown appointment when it's snowing, for example*. (Participant 1)

Reduced patient anxiety was also described as a result of other factors distinct to a telehealth appointment. This participant described how pediatric patients were less anxious when attending a telehealth appointment compared to an in-person appointment. Further, they explained that their assessment of the family's psychosocial and socioeconomic background was improved by being able to see into their home and family dynamics via video conferencing:

> *From a genetic counselor standpoint, there are some things that are really nice. You can see children in an environment in which they're comfortable, so it eliminates the whole doctor fear, in some ways. It allows you to get a glimpse inside of family or home life. That gives you some instant socio-economic, psychological background that's really nice, that you may not capture otherwise.* (Participant 1)

Similarly, another participant expressed an appreciation for telehealth during the COVID-19 pandemic, describing an improvement in their ability to read patients' psychosocial cues via video conferencing, compared to an in-person appointment in which patient and provider are both wearing masks:

> *I think especially in light of the pandemic and having to wear masks, not wearing masks really allows me to read emotions a lot better. As much as something can be lost over video, I think right now, there's also something to be gained that would have otherwise been lost in person*. (Participant 3)

Other participants also described benefits to telehealth that were specific to the COVID-19 pandemic. One participant described that an additional source of patient anxiety, alleviated by the option to attend their appointment via telehealth, was the thought of going into the hospital during the pandemic:

> *We've definitely had people who were anxious about coming to the hospital in the middle of a pandemic. And they were happy that there was an option for telemedicine. So that's definitely been significant.* (Participant 5)

Allowing patients the ability to attend their appointments via telehealth, another explained, communicated to patients that the provider and the institution wanted to provide them with appropriate genetics services, while also keeping them safe from infection with COVID-19:

> *I think for the most part they felt just valued, that we wanted to be able to provide the necessary service for them, and could provide*

> *that - all of their overall care plan in the best way possible that afforded their safety, but also allowed us to gain the information that can be used for their care*. (Participant 2)

Each participant reported an increase in their use of telehealth during the COVID-19 pandemic, and while some of the benefits they described were specific to this moment in time, several others – including reduced patient anxiety, reduced travel time for patients and for providers, increased access to genetics services for patients who previously could not travel or would not have been referred, increased reimbursement, fewer no-shows, and insight into patients' home life – may persist beyond the COVID-19 pandemic.

4.3.2 Limitations of Telehealth

Participants described a variety of limitations to their use of telehealth during the COVID-19 pandemic. Some of these limitations impacted the participants' satisfaction with their jobs, and some impacted their ability to do their jobs in the ways that they would like. Additionally, the limitations described by participants varied with the resources that they had available to them, their practice setting, and what models of telehealth they implemented. While all of these factors are described from the point of view of the participants interviewed, some of the limitations they described also appeared to have significant impacts on their patients. Two prominent sub-themes, Social Factors and Patient Technology, will be discussed in the sub-sections below. First, I will describe the theme of limitations of telehealth during the COVID-19 pandemic.

One participant discussed how patients were not always aware of what was expected of them during a telehealth appointment. Some of these misunderstandings posed barriers to patient focus and understanding, such as calling in to the appointment from a distracting location, while others prevented the appointment from progressing entirely, such as the patient's parents attending the appointment without the patient for a pediatric genetics referral. The participant stated:

> *Some of the other challenges are lack of familiarity with the best practices for telemedicine etiquette for visits. We had a fair amount of people who would be in their car, driving, during a telemedicine visit. Which is - you know, you wouldn't be on your phone in the car in a regular doctor's visit. We had to provide some additional education, so that's a barrier. That does still happen. Sometimes the patient wouldn't be present. Just – I mean, you need to have a patient present for a patient visit*. (Participant 5)

Another participant also mentioned more limited testing options when serving patients in a telehealth setting. The participant described that while it is easier to send saliva kits to patients, there are benefits to performing genetic testing on a blood sample instead. Testing RNA as well as DNA can improve the diagnostic yield of some genetic testing, but RNA testing must be performed on a blood sample. The participant stated:

> *That's the piece, from a medical . . . testing point of view, is the RNA. I'd like to be able to offer that, I'm really not offering it much.* (Participant 4)

While some of these general limitations to the use of telehealth may be impacted by the COVID-19 pandemic – such as patients attending their telehealth appointments from distracting settings due to increased childcare responsibilities, or possibly increased financial barriers to attending telehealth appointments with out-of-network providers – the majority are factors that may continue beyond the COVID-19 pandemic, perhaps influencing how and when telehealth services are offered to patients.

4.3.2.1 Social Factors

Some of the participants interviewed described social factors which impacted their overall satisfaction with telehealth as a service delivery model. These participants described the "human element” missing from their remote interactions with patients and colleagues. One participant stated:

> *But there is a little piece, that human kind of element. You know, just being able to put your hand on somebody. I mean, not that I do that much, but there's a little piece that I guess may be missing*. (Participant 4)

Despite alluding to an ability to provide emotional support and to connect with participants more easily in-person, the same participant also described telehealth in more utilitarian terms, stating:

> *I feel like genetic counseling is so well suited to this. I mean, I used to measure people's heads. If someone had breast cancer I would measure their head, that's it. That's really it. We don't actually really need to touch the patient.* (Participant 4)

Another participant described a missing element in telehealth appointments, particularly when delivering bad news:

> *And I’ll say that sometimes giving bad news can be - it's never easy, but that kind of removed part of being virtual sometimes makes it seem a little impersonal when you're trying to make a connection with someone who's getting difficult news*. (Participant 1)

Both participants described this missing human element as being more apparent in some sessions than in others – cases where they felt the need to “put your hand on somebody” or “make a connection with someone,” to provide psychosocial support in difficult circumstances.

In addition to the ways in which they support their patients, these participants also expressed missing human interaction in general. One expressed being tired of remote interactions, but felt resigned to this new existence:

> *I mean, there's the personal one of - we all kind of have Zoom fatigue. We all have computer fatigue. And we miss that in-person component. But again, you know. You do what you gotta do*. (Participant 1)

This participant also expressed that while their institution had provided resources that may help to address their dissatisfaction and fatigue, accessing them seemed unrealistic, because it required still further time and remote engagement:

> *There have been increased resources for employee well-being. Employee recognition, and the importance of mindfulness, and so forth. But again, those are great when you actually have the time to be able to access those resources, but when you're just constantly working, when are you really going to access those? And those just mean further accessing via Zoom or the computer*. (Participant 1)

In summary, participants described social factors that in some cases limited their ability to provide the level of support to their patients that they felt necessary via telehealth. Further, providing services remotely limited the ways that participants were able to interact with their patients and colleagues, leading in some cases to feelings of isolation and fatigue.

4.3.2.2 Patient Technology

When discussing barriers and limitations to the use of telehealth, participants described problems related to patients' access to the appropriate technology, patients' familiarity with technology, and the variable quality of patients' access to high-speed Internet, all of which impacted the efficacy of a telehealth appointment. For example, one participant described how they had to adjust to phone-only consults for patients without Internet access, in which they could not read patients' psychosocial cues:

> *I'm seeing a little bit with [institution] now, a couple people who don't have Internet. You know, don't have a smartphone or don't have a computer access. And I did my first full phone counseling – yesterday? I think it was yesterday. I honestly really didn't like it. I felt uncomfortable I couldn't tell how we were doing without seeing them. That's just how I felt, I don't know.* (Participant 4)

The same participant later explained that the inability to read their patient's psychosocial cues in a phone-only consult lead them to feel concerned that they were not able to appropriately do their job in this setting:

> *I mean, maybe you get better at it. I'm assuming you get better at it, you develop your skills and you figure out non-visual cues or ways to make sure, but I felt like I didn't do a great job with that one*. (Participant 4)

This participant also described how the quality of a patient's Internet connection, in combination with the patient's comfort with technology, could combine to disrupt a telehealth appointment and damage rapport:

> *That not all people are computer savvy, particularly older patients. That's a barrier. Sometimes the connection not being great, and then you have to go to another platform. And that can break your rapport with a patient*. (Participant 4)

Further, for some patients, using unfamiliar technology to access their genetics appointment was a source of anxiety:

> *I would say it's a really small percentage - five, maybe ten percent, where it seems like it's stressing them out. You know, that it's by telehealth makes it a more stressful experience*. (Participant 4)

Regarding this subset of patients feeling anxious about using unfamiliar technology, the participant concluded that some patients may be better served by in-person appointments:

> *They're probably better off in person. I don't know, it makes me - I feel bad, you know. I feel bad if the telehealth is making them stressed*. (Participant 4)

In addition to impacting psychosocial assessment, rapport, and patient anxiety, participants described other ways in which patient technology limited the efficacy of telehealth appointments. For example, one participant described how the quality of the patient's Internet connection determined their ability to perform a physical exam:

> *Not everybody has good Internet connection, and it significantly impairs your ability to do a decent physical examination if the resolution of the pictures is, if it's just pixels*. (Participant 5)

These concerns related to patient technology are perhaps more prominent in the context of the COVID-19 pandemic. Some participants did offer telehealth services connecting to patients' homes prior to the COVID-19 pandemic. However, during this time period, telehealth appointments primarily took place within patients' homes rather than from one clinical setting to another. As such, one participant explained that some of their colleagues prefer to see patients in-person, but that this preference may be largely due to the challenges they experienced due to the quality of patients' Internet connection:

> *A lot of providers who didn't do any telemedicine before the pandemic are only familiar with a telemedicine visit with a patient in their home. And it's not ideal, especially if you need to do a good physical examination, if the picture's so pixelated that you can't even see the face of the patient. And so, this is the only experience that some providers have had with telemedicine, and it's not been a great experience, they would much rather see people in-person*. (Participant 5)

Patients' limited access to appropriate technology and high-speed Internet – and the resulting limitations to their use of telehealth during the COVID-19 pandemic – could preferentially affect patients depending upon socioeconomic status, as one participant reflected:

> *But, and then, getting patients comfortable with that [telehealth technology] - some obviously more comfortable than others. It speaks to socioeconomic inequities, for some people, they don't have access to Internet or reliable Internet or a computer or a smartphone*. (Participant 1)

The access issues described by these participants, and the ways in which these access issues primarily impact patients experiencing socioeconomic inequity, highlight the idea that the ability of telehealth to increase access to genetics services is not universal for all patients. Furthermore, one solution to inadequate patient technology for at-home telehealth appointments is to have patients attend their telehealth appointments from a clinical facility. However, one participant explained, the hub-and-spoke model of telehealth that they used prior to the COVID-19 pandemic still left out a number of patients:

> *We were limited in in that, in order to bill, we had to bill at a medical facility, so we could only reach people who are within a reasonable driving distance of those facilities. So, there are a lot of people who are not anywhere near those facilities, and we were missing these people. They would either have to drive to [city], or they just wouldn't come*. (Participant 5)

These concerns about limitations to the quality of telehealth consults in the context of telehealth services delivered directly to patients' homes, and limitations to accessing genetics services at all in the context of a hub-and-spoke model of service delivery, inform the upcoming discussion of evolving models of service delivery and uncertainty about the future of telehealth.

4.3.3 External Factors

Participants described a number of external factors affecting their use of telehealth, including outside assistance from organizations like NYMAC, laws and policies governing billing and licensing, and changes to these laws and policies during the COVID-19 pandemic. While some of these external factors facilitated the transition to providing more services via telehealth during the pandemic, others have posed challenges to the use of telehealth. Furthermore, these factors determined what models of telehealth could be used before and during the pandemic, and potential variability in these factors has caused providers to express uncertainty about how telehealth modalities may be used in the future. In this section, the theme of External Factors impacting the use of telehealth will be examined, which will inform the following discussion about the theme of Evolving Models of service delivery and uncertainty in the future use of these models.

Participants described how payer policies for the reimbursement of services provided via telehealth limited the availability of telehealth prior to the pandemic. One participant stated:

> *When the patients are in a medical facility, most insurance companies cover telemedicine, but not all. Some covered it at a lower cost, so it wasn't financially beneficial for the institution, so*

> *they didn't feel that it was a priority. Until a bit later, I think, after they realized the benefits of telemedicine, and the number of people that we can help - and, when billing was possible for telemedicine, they've kind of turned around*. (Participant 5)

The variable coverage policies made it difficult for institutions to invest in or commit to providing services via telehealth. Furthermore, payer policies dictated the setting for telehealth services, as the same participant later described:

> *It was difficult because not everyone paid for telemedicine, there wasn't a huge financial incentive for the institution to provide telemedicine before the pandemic. And we were limited in that, in order to bill, we had to bill at a medical facility, so we could only reach people who are within a reasonable driving distance of those facilities. So, there are a lot of people who are not anywhere near those facilities, and we were missing these people. They would either have to drive to [city], or they just wouldn't come*. (Participant 5)

In other words, some institutions did not provide telehealth services directly to patients' homes, because payers would not reimburse them for these services. At the beginning of the pandemic, these policies were relaxed, allowing rapid expansion of telehealth. One participant stated:

> *They started to transition a little bit before because, like I said, they declared that it was a priority before the pandemic. And they had started to make some inroads there. But once billing was available for patients in their home, it exploded, and it has continued since then*. (Participant 5)

This participant's experience with telehealth prior to the pandemic was informed by their institution's early prioritization of telehealth, while another explained that at their for-profit institution, billing and reimbursement concerns prevented their use of telehealth prior to the pandemic. As soon as these billing and reimbursement restrictions were relaxed at the beginning of the pandemic, they were able to offer services via telehealth:

> *What helped facilitate it was really learning that we could bill for the service. That was the big deal. I work for a private facility, so it is for-profit, and it had to be something that could bring in as much*

> *value - and I guess I would say the legislature that changed during COVID that made it more – the rules became a little bit more relaxed because of COVID, so I think that helped from a billing perspective as well*. (Participant 3)

Licensure laws also posed a problem. Prior to the pandemic, physicians had to hold a medical license in the states their patients were physically located in during the consult. Similarly, genetic counselors had to be licensed in their patient's state, if that state required licensure for genetic counselors. One participant described previous efforts to simplify licensure, and why it was not helpful for them:

> *There's the interstate medical licensure compact, but it's not really making things a lot easier, or certainly less expensive. You still have to get a license in every state, it just facilitates it a little bit. So, we see a lot of patients in other states, and if there isn't less restriction of the licensing after the pandemic is over, then it's just going to go back to the way that it was, and you won't be able to see those people*. (Participant 5)

Once these licensure laws were also changed during the pandemic to facilitate the use of telehealth, providers were able to "see" patients in their out-of-state homes. Because these dramatic changes in licensure laws and in how payers reimbursed for telehealth services – allowing for providers and their institutions to offer telehealth services directly to their patients' homes, even for those living out-of-state – began in response to the COVID-19 pandemic, participants expressed a desire to maintain these changes to allow telehealth services to patients' homes to continue. When asked about desired policy changes, one participant stated:

> *So, I think, keeping the ability to bill in different telemedicine modalities, and lifting of licensing restrictions, or keeping them lifted, or making it easier to facilitate licensing in multiple states*. (Participant 5)

Another expressed desire for permanent policy changes allowing them to provide services to their patients regardless of location – relating to the billing and reimbursement issues, as well as the licensing issues, described above:

> *Making permanent the . . . opening of where telemedicine has to originate and locations and so forth. You know licensure will continue to be an issue until there are some – even physicians can't cross, they have to have licensed in certain states, so a national licensure thing isn't gonna work. So, it really has to be a matter of making sure that the recognition that you can provide the same services and therefore should get the same reimbursement from a telehealth setting* . . . (Participant 1)

Because of the policy elements of reimbursement and licensure, one participant expressed that regular policy updates from organizations like NYMAC would be helpful to them:

> *I think updates on what's going on federally and statewide, as well, because I know some of the restrictions are for state-by-state. That would be really helpful, if they can keep up with the pulse of things and have some kind of legal update that comes out once a month, quarterly, whatever it may be. That would be really helpful.* (Participant 1)

Another participant requested advocacy for lasting policy changes, to allow reimbursement for telehealth services to continue. They also suggested that in absence of such lasting policy change, funding from NYMAC could allow institutions to provide these services to underserved patients who are unable to travel to the clinic:

> *I mean it unfortunately all comes down to reimbursement, so just making sure that if we are still utilizing that service, that either they're advocating for us on a higher level, to make sure the billing restrictions don't tighten up, or if they do tighten up, maybe make at least available some funding to help do the telegenetics for maybe an underserved population that's going to have difficulty coming into clinic*. (Participant 3)

Participants also highlighted other concerns relating to billing and licensing. One expressed a desire for multi-state or national licensure for genetic counselors:

> *It would be helpful if I could bill for myself, which would require genetic counselor licensure in [state] and beyond. That would just simplify the process*. (Participant 3)

And several participants said that CMS recognition of genetic counselors as healthcare providers, which would allow Medicare to reimburse for genetic counselor services without a supervising physician, would simplify their practice for both in-person and remote service delivery. As one participant explained:

> *I think that policies from CMS just to recognize genetic counselors, period, would be good, so that it wouldn't hinder any of our type of services that we offer. I think all of us still would like to see that, obviously there's a bill that's back out there now that would help with that.* (Provider 2)

The same participant also explained that providing services to their Medicare patients took an extra level of planning, because it required them to be physically located at a facility, near the physician:

> *Being mindful of a particular payer, and if it was a CMS payer, obviously counselors can't bill for all that. Being aware that you needed to be near a provider, that you needed to think through how would you do it*. (Participant 2)

Another participant described how, as a privately practicing genetic counselor, they have struggled to coordinate billing and reimbursement. This participant also expressed the need for CMS recognition of genetic counselors, but described another layer of difficulty – without an institution, they have had to coordinate credentialing with insurance companies on their own, in order to be reimbursed by their patients' insurance:

> *I'm out of network. So, it's a challenge. It's the whole, you know, we need to get recognized by Medicare. I'm doing some work. But I completed this thing called CAQH which is basically like this huge profile to try to get credentialed with insurance* . . . (Participant 4)

In addition to describing desired resources, participants also mentioned resources that were helpful to them in transitioning to providing more services via telehealth. Some of these resources were provided by external organizations like NYMAC, NSGC, and various genetic testing laboratories, while in other cases, participants described assistance and resources they had received by collaborating with other genetics providers.

Several participants described attending conferences and training programs through NYMAC, expressing that they felt more comfortable and confident in providing these services afterwards. For example, one participant stated:

> *Last year I was able to participate in the training program through NYMAC, that I think really helped in creating what I thought was a good way to coordinate that for folks [. . .] I thought I felt pretty comfortable with it, especially after having some of the training and going through those modules, it was very helpful*. (Participant 2)

Others described how not only was the information helpful, but having connections within NYMAC who could answer their questions was also reassuring. One participant stated:

> *I did participate in one of the NYMAC conferences, where I learned telegenetics tips, and that was really helpful to not only give me information, know that there were people that I could turn to if I had questions, and really just give me the confidence that it was something that was doable.* (Participant 3)

Participants also appreciated patient education materials from NYMAC and other organizations, as well as from other providers they connected with through these online listservs. One stated:

> *So NYMAC, I think before the pandemic – and not just NYMAC, but some of the other organizations – published online best practices and videos for how to do a telegenetics visit, or what is appropriate, how to have the appropriate lighting. And we used those, and sent them to patients in advance of their visit, so that was very helpful. Those media resources were extremely helpful*. (Participant 5)

In addition to resources, listservs and professional organizations such as NSGC were helpful to providers to share the results of their problem-solving with others in similar situations. One participant stated:

> *NYMAC and other [NSGC] cancer SIG groups - I think they were all very helpful in bringing up concerns. And it's probably, unfortunately, it was like – oh, I just encountered this, so I'm thinking it's going to be this way, or does anybody else already thought through that or encountered that, and maybe they've come up with a solution that worked in their center*. (Participant 2)

One participant described how important funding from NYMAC had been to developing their institution's hub-and-spoke model of telehealth prior to the COVID-19 pandemic. The funding allowed the institution to expand the telehealth practice by purchasing equipment for two satellite sites, as the participant stated:

> *NYMAC was the main outside institution. They provided grant funding so that we can purchase peripherals for the [city] and [city] clinics*. (Participant 5)

Several participants agreed that they would like to see similar help from NYMAC in the future, including additional trainings, information about evolving best practices for telegenetics, and additional funding. They also described the potential value of resources distributed by genetic testing laboratories. One participant said:

> *Continuing to do what they've already done. They've been super helpful with providing the media that we talked about, opportunities for funding, reaching out - NYMAC does an excellent job of reaching out to their providers, which I really, really appreciate. I think doing a lot of what they've already been doing would be great*. (Participant 5)

Though online tools to collect and coordinate family history information, such as the CancerGene Connect tool mentioned by this participant, may be useful for remote clinical practices, the participant expressed concern that such resources are not truly "free" to use, and that they require providers to agree to sharing their patients' data.

To summarize, when discussing external factors that affected their use of telehealth, participants described licensure and reimbursement policies that made the use of telehealth difficult prior to the pandemic, as well as changes in these policies that helped to facilitate their use of telehealth during the COVID-19 pandemic. In addition, they described other policies, such as how state or national licensure for genetic counselors, as well as CMS recognition of genetic counselors as healthcare providers, might help to facilitate payer coverage of genetic counselor services. Participants described how resources created by organizations like NYMAC and NSGC, as well as remote collaboration with other providers, helped them initiate or improve their telegenetics practices. Finally, resources created by laboratories were described as another potential tool to simplify aspects of a remote genetics practice, with the caveat that such services may impact patient privacy.

4.3.4 Evolving Models

Participants described how their use of different service delivery models changed during and throughout the COVID-19 pandemic, how they anticipated these models might continue to evolve, and how they hoped these models might be used in the future.

Some of the participants described holding regular telehealth clinics prior to the pandemic, with a hub-and-spoke model where patients attended their appointments from another clinical location. For example, one participant stated:

> *Prior to the pandemic, I had a weekly telemedicine clinic in [city] and [city], and the patient would go to the medical facility there, the satellite of our hospital, and nurses there would act as telepresenters*. (Participant 5)

Others had previously provided services via a hub-and-spoke model of telehealth, but only sparingly. Factors such as having to set aside time specifically for telehealth and competing with other departments for access to electronic equipment determined their ability to provide services via telehealth. For example, one participant expressed:

> *Before the pandemic, we had our telemedicine suite that was for the entire institution, it was always in use, and it was highly desirable. And no one department was ever getting as much use of the telemedicine suite as they would want.* (Participant 1)

As a result, some participants who had previously used telehealth sparingly more often drove from their primary clinic to satellite clinics to provide in-person services to their patients at these other locations. Other participants had no prior experience providing services via telehealth, at least in part due to their institution's concerns about being reimbursed for these services. Billing and reimbursement policies changed at the start of the pandemic, allowing rapid implementation of telehealth services. One participant explained:

> *They were interested in being able to reach more distant patients, but they were worried about billing. So, basically, they didn't really do any research into billing until push came to shove, and that was really why we implemented the telegenetics service*. (Participant 3)

In addition to now being able to bill for telehealth appointments directly to patients' homes, another participant explained, at the start of the pandemic, this new model of telehealth was the only option for delivering services to patients:

> *I mean, the fact that people couldn't come in in-person was a big reason - the main reason, really. People either didn't come, or they had a telemedicine visit. Because initially, we were not allowed to see anyone in-person. We either had to cancel appointments or offer a telemedicine visit*. (Participant 5)

As a result, some institutions that had already been offering telehealth services to a subset of their patients experienced a renewed sense of urgency to expand the service. One participant expressed:

> *It's mostly been accelerated because of the pandemic. Prior to the pandemic, they were thinking about these things and planning to do them, but it was moving at a very slow pace, and there wasn't a lot of impetus to get it done in a timely manner.* (Participant 5)

While institutions rapidly expanded the availability of telehealth services more generally, the types of telehealth service delivery models used shifted during the beginning of the pandemic. While the use of video conferencing and phone-only consults directly to patients' homes increased, one participant explained of their hub-and-spoke clinics:

> *They decreased, actually, because we had people going to the medical facilities, and initially, during the pandemic, nobody was going to medical facilities, so those decreased, and then we*

> *increased telemedicine with the patient at their home*. (Participant 5)

While patients primarily accessed telegenetics services directly from their homes during this time, the participants' locations varied. Some participants described working exclusively from home, while others adjusted their schedule to accommodate payers that required they access their patients' telehealth appointments from a clinical space:

> *I did work from home for a good bit of time again, unless there were constraints for patients' insurance. Usually, we would try to set those patients up for basically one day where I would come physically into the office, just to meet all the criteria for an incident or being near the provider who was there to care for - their medical oncologist. But yes, I would work mostly remotely from my home location and just created a confidential office area there.* (Participant 2)

At the beginning of this transition to providing more services via telehealth, participants described a number of changes to service delivery. For example, one participant described focusing their efforts primarily towards consultations for patients who needed the information urgently for their cancer treatment:

> *Prior to the pandemic, proportion of the folks that I would see were due to family history, and [since the beginning of the pandemic] we really limited the interaction and risk assessments to cancer patients who really needed it for their care plan, and just pushed and continue to push out those risk assessments for folks with family history, feeling that those were still able to wait for some period of time until we felt comfortable with seeing those patients back in the office here*. (Participant 2)

Participants described ongoing adjustments to their use of technology as they worked towards greater efficiency in how they provided services via telehealth. These adjustments included troubleshooting and re-training on new platforms, as well as developing additional processes to make sure patient and provider were on the same page about the platform that would be used for each appointment. For example, one participant explained how their department struggled with technological difficulties impacting their use of interpreters:

> *One of the transitions right now is, our interpreters were actually – in-person interpreters were getting on Zoom with us, and that was nice. Now they've been forced back to completely in-person. So now we're having to use Marty, which is a video system that conferences in with Zoom, but those have gone down frequently.* (Participant 1)

Some participants were able to return to clinic after only a short period of time, to provide services to patients primarily in-person, while others have remained completely remote. One participant described a practice very much in-flux, due to increasing COVID-19 case numbers in their area:

> *We are back on our third round of going in-person for some of these outside clinics. The first one was the initial, I guess it was like maybe June when things started easing up, in 2020. At that point, first wave was over, we had outside pressure to come back and staff those outside clinics, and we started doing that. And then, second wave came. And we pulled back on some of those, and then tried to initiate - and then started to kind of creep back in a little bit. Then Christmas came and then we went completely back into a whole, everything's got to go virtual again because we've been hit really hard, as everyone did with the third wave. And now we are back into, we're all fully vaccinated, or those who choose to be fully vaccinated, and going back into the clinics that are putting pressure.* (Participant 1)

For participants returning to clinic to provide services in-person, some modifications to service delivery have remained. For example, one participant described their new clinic policy that does not allow patients to bring visitors with them:

> *We've tried to link the time up with seeing their provider, so we are limiting the number of visits that they have, and we've certainly put in place limiting the number of – well, where I'm at, I'm at the cancer center, so there was no visitors, no extras, you know, that could come with [the patient].* (Participant 2)

As some appointments have been able to return to the in-person setting, some participants expressed being able to exercise a greater deal of flexibility in the service delivery models they are able to use to see their patients. For example, one participant described an increase in the number of hub-and-spoke telemedicine clinics offered within their department, as well as an increase in the number of telehealth appointments directly to patients' homes, as necessary:

> *After we were allowed to see in-person visits, I would say that most of our volume has recovered. We still have more telemedicine clinics than we did before the pandemic started. [. . .] And then intermittently, our other providers, who are not doing any regular telemedicine visits, they will intermittently have a telemedicine visit here or there with one of their patients, usually those who live pretty far away. We see a lot of patients who live very far away, so it's quite helpful.* (Participant 5)

The same participant described their institution's goals of continuing to expand hub-and-spoke telehealth services following the pandemic, dependent upon the availability of additional funding to purchase equipment for new clinics:

> *There has been some difficulty with funding, so now that people are able to go to medical facilities, the institution still wants to expand telemedicine, but they're having difficulty identifying funding to provide appropriate peripherals in the medical facilities to allow for a better physical examination, which is much more possible when a patient is in a medical facility than when they're at their home*. (Participant 5)

Another participant described that although their institution had similar goals, these aims were being delayed due to the pandemic:

> *Not that it's [expansion of hub-and-spoke] fallen off the radar, but I think doing what we're doing now is kind of the focus to get through the remainder of – well, whatever the remainder of this is*. (Participant 2)

Others expressed that they would continue to provide telehealth services directly to patients' homes, and perhaps some in-person services as well, now that it was clear to their institution that genetic counseling services did not require the additional electronic infrastructure of the hub-and-spoke model:

> *I think now that they have seen that there are a variety of ways that telehealth can occur, and as long as these pandemic-related guidelines stay in place about the location and so forth of telehealth, I think they're in favor of those moving forward, so that there will always be some hybrid nature. That we won't go back to 100% in person, nor would we do 100% virtual*. (Participant 1)

As alluded to by the participant quoted above, several participants also made it clear that although they wished to keep remote options in place for their patients, the future use of these telehealth service delivery models depends upon continuing patient demand, as well as whether current licensing and billing policies remain in place. When asked what policies may help to continue offering these services, one participant explained:

> *So, I think, keeping the ability to bill in different telemedicine modalities, and lifting licensing restrictions, or keeping them lifted, or making it easier to facilitate licensing in multiple states*. (Participant 5)

Supposing such licensing and billing policies allowing for the use of telehealth to patients out-of-state and to patients located at their homes during the time of service remain, one participant anticipated that their institution would establish more firm guidelines in how they use these models:

> *I think that there will be some more guidelines coming into place as the pandemic winds down. And I think they'll be less, it's all just unfolding and we'll just deal with it as it is, and more, this is how things will occur, this is what ratio your telehealth to in-person should look like, and so forth*. (Participant 1)

Another suggested that new service delivery models will continue to emerge, describing the possibility of telehealth services offered to patients located at public libraries, for Internet access and technical assistance:

> *I'm thinking you go to a library and you could take a booth, and. I think that that would be helpful, maybe even for the older folks if somebody at a library could help someone*. (Participant 4)

Participants described a number of changes in how they provided genetics services to their patients at the beginning of the COVID-19 pandemic, as well as how these services evolved throughout the course of the pandemic. Though these participants' experiences with telehealth prior to the pandemic varied from no prior experience to regularly offering hub-and-spoke telehealth clinics, each envisioned a future in which telegenetics services were more routinely available to patients. Participants also described how this future use is contingent upon continued patient demand, clinical setting, institution policies, and the licensing and billing policies governing where patients and providers must each be located during a genetics appointment.

4.3.5 Provider Adaptation

Participants described many ways in which they adapted to changes at the beginning of the COVID-19 pandemic, specific to the service delivery models chosen by their institution, their patients' needs, and the needs of other clinics, departments, and colleagues with whom they work. Most commonly, participants described a willingness to be flexible, as well as ways in which they became more flexible, in order to continue providing services to patients. One participant, who had previously provided services to patients under a hub-and-spoke model of telehealth, described how they became more flexible by changing their model of seeing patients during the pandemic:

> *I think that I have become more flexible in my provision of telemedicine. So previously, with my clinics in [city] and [city], I required one in-person visit in [city] before we would see anybody at those satellites, because there are certain things that you can't do via telemedicine on a physical examination. And the pandemic would not let us do that anymore. So now we see new patients via telemedicine for the first time, which we didn't do before, we only saw return patients. So I've become more flexible in that regard.* (Participant 5)

As a result, the same participant described an improved ability to determine whether a patient must be seen in-person or via a different modality:

> *Not everybody needs an in-depth, detailed physical examination for their appointment, so I think it's important to keep in mind that you can be flexible and tailor the patients that you see in the different modalities, whether it's in-person, telemedicine via a medical facility, or telemedicine in their home, depending upon the reason for the visit. And so that's - it's important, and it ends up providing more care to more people who need it. There's not a lot of*

> *geneticists, so we need to kind of find a way to see people who need us.* (Participant 5)

The participant described how this attention to the patient's needs – including the medical situation, the patient's distance from the primary clinic and satellite clinics, and the technology available to the patient – can help to remove or reduce barriers to accessing genetics services.

Other participants described ways that they adapted to their patients' needs in a fully remote context. For example, one participant described anticipating and adjusting to patients' familiarity with technology when asking them to fill out information ahead of an appointment:

> *There's also a fair amount of information that I try to get patients to complete in advance and I've learned - don't overwhelm the patients who either are older, or just seem like they're not comfortable computer-wise, so. Let them just do online consents. I won't try to encourage a patient who I think is having technological challenges to do the Progeny family health questionnaire, or things like that. So, adjusting a little bit, on a case-by-case basis, I think it's helped to some extent*. (Participant 4)

These case-by-case adjustments, the participant explained, can help to reduce patient anxiety about attending a telehealth appointment.

Several participants also described being flexible about the specific types of technology used, to accommodate patients who do not have access to the appropriate technology or high-speed Internet access. For example, one participant stated:

> *The patients are always seeing me on video, with the exception of when we have technological issues, and then we'll utilize phone only. Sometimes the patient is at their home and sometimes the patient comes into our previous clinic office, but I'm always located at home*. (Participant 3)

Another described that in their new service delivery model, in which they provide services primarily via phone consult and therefore do not have the opportunity to visually assess patient cues relating to understanding, they have adjusted to patient needs by offering information through multiple modes of communication. The participant stated:

> *I felt very comfortable doing it and making sure that the communication was as good, and their risk assessment was as helpful as possible. I've always continued to document those interactions and send patient summary letters of their information, so I felt like there was still another mode to communicate*. (Participant 2)

Participants also described becoming flexible about their location of practice to meet payer requirements. In one example, the participant described working with their institution to schedule in-person days each week, to meet CMS guidelines for reimbursement:

> *My office and [clinic] had, in the beginning, instantly identified providers that could work remotely, and I'm like oh yeah, I can work remotely, no problem, and then we identified that piece of it and I'm like well I need to be in the office preferably one day a week so that I'm near and connected to the providers for these specific payers and just line up their schedule that way*. (Participant 2)

In addition to becoming more flexible, participants described new or evolving roles as leaders within their institutions during the COVID-19 pandemic. For example, one participant described how their formal leadership role evolved during the pandemic, to help guide their institution's widespread implementation of telehealth services:

> *Prior to the pandemic, a telehealth steering committee had been formed, of which I am a member, that was before the pandemic, but it turned out to be quite fortuitous because that is the group that ended up forging a lot of the practices that we've been using during the pandemic*. (Participant 5)

Another participant described an informal role as an expert at their institution, as the only practicing genetic counselor at their facility:

> *I'm the only genetic counselor here and their first genetic counselor here, so they're very receptive to whatever ways that we can make sure we're incorporating the right service. They usually will look to guidance from me to provide those services, and as long as we're communicating with leadership about the right way to do it from safety that exists for the whole system*. (Participant 2)

In this case, the participant's institution looked to them for their expertise in what was necessary to provide genetics services to their patients appropriately during this time. Another participant also described an unofficial role as an expert, in which they and their department worked to solve problems for other clinics where they provide contracted work:

> *I think any addressing of issues, barriers, and so forth, have all been troubleshooted through our own department, and coming up with the answers for the outside places.* (Participant 1)

In another type of leadership role, one participant described how the pandemic led to their decision to open their own practice:

> *Basically, I set up my business. Yeah, setting up the practice, it gave me that clear direction. You know, as to - okay, it's looking like this is how it's going to be for a while, and run with it*. (Participant 4)

In their new role as both institution and provider, they had to adapt to providing services via telehealth completely on their own.

In summary, some of the adjustments that participants have made are in anticipation of what the patient may need, while in other cases, participants used this new flexibility model to make adjustments on the spot, switching from one platform to another as necessary for patient care or to follow appropriate requirements for billing. Each participant displayed a great deal of flexibility in how they worked to provide services to patients remotely during the COVID-19 pandemic. Several took on new leadership roles or found their current leadership roles greatly expanded. Whether practicing under a broader institution or acting as their own institution, they managed to adapt their work to rapidly implement telehealth services for their patients.

4.3.6 Institutional Engagement

Participants described varying degrees of engagement from their institutions, as they transitioned to providing more services via telehealth during the COVID-19 pandemic. In this section, the relative levels of institutional engagement will be discussed, along with any factors that helped to mitigate difficult institutional practices.

On one end of the continuum, participants described working in institutions that were actively engaged and receptive to their needs during this time. Some of these participants' institutions were already working to increase the availability of telehealth to help meet patients' needs prior to the beginning of the pandemic, which contributed to their overall readiness. One participant stated:

> *I've been at this institution for about five years, and in the beginning, it was not as much of a priority as it was later years, so it's difficult when it's not a priority for the institution, especially if you can't bill the same. [. . .] Until a bit later, I think, after they realized the benefits of telemedicine, and the number of people that we can help, I think that - and, when billing was possible for telemedicine, they've kind of turned around*. (Participant 5)

In describing how their institutions were helpful to them, participants detailed how their institution kept them updated about changes throughout the beginning of the COVID-19 pandemic and provided informational material to help them prepare to offer these services to patients. For example, one participant stated:

> *They provided a lot of educational material to the providers. They regularly send out emails regarding telemedicine, especially during the initial portion that pandemic. They regularly sent out education materials for how to use the new technology. And so, communication was big, and impressive for the institution. I was really happy with the level of communication that they had with telemedicine in beginning of the pandemic, it was really helpful. They did a good job*. (Participant 5)

Participants also described ways that their institutions invested in additional equipment, software, or IT support to help them provide services via telehealth, particularly as these needs changed during the pandemic. One participant described:

> *I felt like the [clinic] provided me with the necessary equipment to work remotely and feel comfortable with that. They provided me with cell phone, computer things, all the things that were necessary*

> *for that. And just ways to log in from connect remote, so that you felt you were securely connected but able to see all the applications that you were if you were physically on site. I thought that was good, they were very quick to make that, and we still have that capability, so that's been helpful*. (Participant 2)

These actively-engaged institutions demonstrated their receptiveness to providers' needs by eliciting provider feedback and guidance, whether through a formal position on a steering committee or less formally. One participant described:

> *I've only been working with [institution] for a few weeks, but they're just completely open to the different ideas of how to do things.* [. . .] *They've been open to hearing about different kinds of ideas, and just being part of a whole organization, there's a lot more support*. (Participant 4)

Further along the continuum are descriptions of mixed messages that participants received from their institutions. One participant explained that although their institution communicated that telehealth was a priority, in reality, the demand for the existing telehealth infrastructure far surpassed its actual availability. When they communicated additional needs to their institution, the participant explained, the institution recognized the problems but did not address them in a meaningful way. The participant stated:

> *I think they've always been proponents of telehealth, but again, had a very small telehealth suite that was always incredibly in demand. And you know we said, we want to add another telehealth clinic - "oh, there's not space for this," or whatever. They could say they were supportive, but in reality, there wasn't a built-in infrastructure*. (Participant 1)

At the beginning of the COVID-19 pandemic, some participants felt that their institutions provided very broad guidance, giving individual departments the autonomy – but also the responsibility – of establishing new service delivery models independently. For example:

> *I mean, they basically said that if I could make it work, I could do it. So it was more work on my end, and my assistant's end with the logistics, and then on our billing department to figure out the billing aspects*. (Participant 3)

This experience was relatively similar for a participant practicing as an independent provider, without an over-arching institution. They expressed satisfaction with the level of control they had over how they chose to practice, but also described a great deal of set-up work:

> *I could look at them [EHRs], get demos, see the pricing, see what they could do, figure out how I wanted to integrate everything, and so. From getting a phone, an e-fax, figuring out how do you make sure that you're HIPAA compliant. Selecting an EHR. And the EHR itself . . . the one I picked wasn't intended originally for telehealth, so they had just added the telehealth component to it. I'm trying to think of what else - a website. You know, requesting appointments online, like it's - everything. Oh, everything*. (Participant 4)

Some participants working at less engaged institutions felt that their needs – whether for space, information about future plans, or other concerns – were less significant when compared to the needs of the larger institution or of other departments. For example, one participant expressed that their department had no choice in transitioning to providing telehealth services from their own homes during the pandemic, because their needs were put in direct competition with those of other clinical departments:

> *We don't have designated clinical space, so all of our clinical space is shared with other specialties. We share with neurology, we share with cardiology, and so forth. When it comes to kind of essential services and the appointments that absolutely have to get in-person, ours really didn't quite hit that level of - can we really say we hit the same level as having to go for a cardiology appointment because you're, had a recent heart attack? Probably not, right*. (Participant 1)

Others felt that their institutions resisted some aspect of remote telehealth services. For example, as one participant stated:

> *I think they simply did not want employees working from home essentially at all, prior to the pandemic. So, it was almost like easing into remote work.* (Participant 3)

One participant felt that they had to manage expectations from several different sources, including those of their broader institution, their individual department, the university whose students they helped to train, and outside clinics where they were also contracted to provide services. This participant described being in the position of having to defend their use of telehealth to one such outside clinic in the face of active resistance:

> *There also has been a little bit of resistance of, "well, you should just be here in person no matter what, you're an essential employee." And trying to make the case of, well, we're really not taking up any extra space by not being present, and we're providing the same service, and we're providing the same testing options, we're just doing it in a way that looks a little bit different. So, we've made some headway in some of the practices, and other practices, I know as soon as the pandemic really starts to wind down for good, whatever that may look like, we'll be back in-person 100%.* (Participant 1)

These participants practicing with no institution, experiencing elements of lower institutional engagement, or even of active resistance from their institution or clinics where they provide services, described a number of mitigating factors that helped to facilitate their use of telehealth even in these circumstances.

Participants mentioned how important support staff like genetic counseling assistants and representatives from the institution's billing department were in helping them set up and run their clinics via telehealth. For example, one participant expressed:

> *Currently, with [Institution], I have a genetic counseling assistant, and we kind of have an agreement that I'm going to do it the same way that I said I did, reach out when I can, and then, if I missed the patient, I can leave them a message and they'll call back and be able to have [assistant] schedule that time. Just, which is lovely.* (Participant 4)

Participants also described their colleagues and their departments as useful resources. For example, one participant described guidelines established by their department for telehealth appointments:

> *And so we've instituted - basically, guidelines. And if someone is on their phone or in the car, or the patient is not present, we just reschedule the visit. So, we've been able to manage those difficulties.* (Participant 5)

Additionally, another participant described technology upgrades that would help to improve and unify their institution's approach to telehealth:

> *I think that our [institution] will roll out its own individual platform that we won't be relying on Zoom or Teams or whatever. And I believe our new EMR, electronic medical record transition, there is some of that modality built in, and that come - that rolls out in December of this year. I think that transition will then make it more, there is more continuity across all the departments and how they're offering telehealth.* (Participant 1)

Participants described substantial differences in the level of engagement exhibited by their institution throughout their transition to providing more telegenetics services during the pandemic. On one end of the continuum, participants described institutions that were receptive to their needs and actively involved in helping to meet those needs. At the other end of the continuum, participants described clinics which actively resisted the transition to telehealth. Participants also described independent practices, and institutions that were less engaged, but generally permissive of their provision of services via telehealth. For those experiencing less engagement and receiving less assistance from institutions, other factors such as support staff, department and colleague support, and technology upgrades helped to mitigate the lack of institutional support.

4.4 Discussion

During the COVID-19 pandemic, healthcare providers across specialties rapidly implemented telehealth services to avoid interruption to their patients' care while also protecting both patients and providers from infection with COVID-19. While a few perspective pieces and surveys have recently been published, this study seeks to gain a deeper understanding of the perspectives and experiences of genetics providers within the NYMAC region who transitioned to providing telegenetics services during the pandemic.

To pursue this goal, five semi-structured interviews were performed. This process elicited six themes and two sub-themes, as previously shown in Table 11. The themes are each inter-related, as shown in the thematic map (Figure 8) below. Discussions of each theme can be found in the following sections: the Theme of the Benefits of Telehealth; the Theme of the Limitations of Telehealth and its Subthemes, Social Factors and Patient Technology; the Theme of External Factors; the Theme of Evolving Models; the Theme of Provider Adaptation; and the Theme of Institutional Engagement. A discussion of study limitations and future directions will follow.

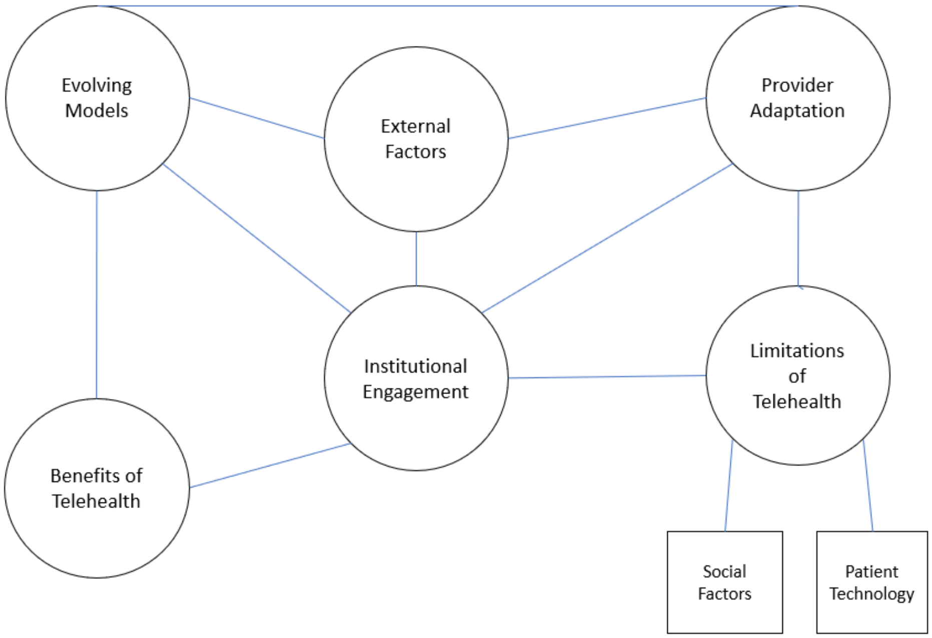


Figure 8. Thematic Map.

4.4.1 The Theme of the Benefits of Telehealth

Participants described a number of benefits to the use of telehealth modalities – some specific to the COVID-19 pandemic, and some possibly more broad-reaching – and how these factors benefitted not only themselves, but also the patients they serve and the organizations they work for.

Participants described how the use of telehealth directly to patients' homes has reduced travel time for both patients and providers, increasing access to genetics services for patients who live prohibitively far from genetics clinics. These benefits were also described by providers participating in studies prior to the COVID-19 pandemic regarding their use of alternative service delivery models, including telehealth (Boothe, Greenberg, Delaney, & Cohen, 2021; Cohen, Huziak, Gustafson, & Grubs, 2016), and likely will remain strong selling points for telegenetics services, whether delivered directly to patients' homes or to satellite clinics in a hub-and-spoke model of telehealth. Furthermore, in this study, participants also described how the reduction in travel time for their patients has also encouraged additional referrals from referring providers, which does not appear to have been described by similar qualitative studies in the past (Boothe et al., 2021; Cohen et al., 2016; Khan, Cohen, Weir, & Greenberg, 2021).

In addition to resolving the barrier of physical distance to genetics clinics, participants described how patients experienced less anxiety related to travel and city traffic, and were more likely to come to their appointments as a result. Fewer no-shows have been described as a result of implementing telegenetics by other studies in the past (Khan et al., 2021), and in this study, one participant described how their department's reimbursement rates have improved as a result. Even for patients living close to the clinic, one participant explained, telehealth appointments were more convenient, saving a great deal of time that would otherwise have been spent on the logistics of travel, parking, and waiting for the appointment. Other studies have described this increased convenience in terms of patients who live close to clinic but might have a long bus ride to come in-person (Boothe et al., 2021), as well as in the context of the COVID-19 pandemic, in which some patients may work from home or have increased childcare responsibilities (Aziz et al., 2020). These convenience factors may continue to entice providers and institutions to keep telehealth options in place following the close of the pandemic – as one participant in this study described the aspect of convenience as a selling point for prospective clients of their private practice. Though some of these benefits seem especially prominent in the context of the pandemic, in which a greater proportion of the population worked from home, the ability to attend a telehealth appointment without requesting time off work was also described as a benefit before the pandemic (Cohen et al., 2016). In other words, the pandemic may have simply illuminated to a broader public how convenient telehealth can be in various situations.

In this study, as in another study completed near the beginning of the COVID-19 pandemic, participants described how some of their patients experienced less anxiety in telehealth appointments due to less "doctor fear," or worries about blood draws or invasive testing following the appointment (Pereira et al., 2020). In addition to less "doctor fear," participants in this study described other psychosocial benefits that apply to telehealth services offered directly to patients' homes even outside the context of the pandemic, such as the ability to see into patients' home life as part of a psychosocial assessment. This may have been less frequently described in the past, due to a higher proportion of telegenetics services taking place in a satellite or hub-and-spoke model rather than directly to patients' homes. Participants also mentioned other psychosocial benefits of telehealth that were specific to the pandemic – such as alleviating patients' anxiety about possible infection with COVID-19 in a hospital setting, being able to read patients' emotions more efficiently without masks, and communicating to patients that they are valued by prioritizing their health and safety. These possibly newly defined benefits of telehealth specific to the COVID-19 pandemic help to illustrate the unique problems addressed by alternative service delivery models during this time. Though some of the problems solved by telehealth were specific to this context, others existed prior to the pandemic, suggesting that the utility of telehealth demonstrated during this time may encourage some providers and institutions to continue its use beyond the pandemic.

4.4.2 The Theme of the Limitations of Telehealth and its Subthemes

Participants also described a number of limitations to their use of telehealth during the COVID-19 pandemic, including some general limitations as well as limitations related to social factors and limited patient technology, some of which impacted the providers' job satisfaction or their abilities to do their jobs properly. They also discussed ways in which these limiting factors affected their patients.

One such limitation described by participants in the course of these interviews was patients' unfamiliarity with telehealth best practices. Occasionally, one participant explained, patients would attend their at-home telehealth appointments from inappropriate settings, or a patient's parents would present to the appointment without the patient. Distractions during at-home telegenetics appointments have been described by other studies prior to the pandemic (Khan et al., 2021), as well as during the COVID-19 pandemic (Pereira et al., 2020).

In this study, participants also mentioned how patients seen in telehealth appointments may be offered different testing options than patients seen via in-person appointments. In particular, one pro participant explained, a genetic testing panel including RNA studies could be performed on a blood sample, but it was easier to coordinate saliva or buccal samples for remote patients. Though they did not describe limitations on the types of testing offered to patients, another study conducted during the COVID-19 pandemic described difficulties in coordinating sample collection (Bergstrom et al., 2021). It may be that practice setting played a role in how participants experienced issues with sample collection; in this study, the participant who described limiting their use of RNA sequencing had their own private practice, without an official clinical office location where patients could present to have their blood drawn.

Despite some psychosocial benefits to telehealth appointments during the COVID-19 pandemic, participants also described missing the "human element" of interacting with their patients, particularly when delivering difficult news. Furthermore, they missed interaction with their colleagues, expressing fatigue and isolation as a result. Other studies have similarly described challenges to establishing and maintaining rapport with patients in telehealth appointments (Khan et al., 2021), as well as concerns for potentially lost working relationships with colleagues during pandemic-induced isolation (Bergstrom et al., 2021). Practice setting may again play a role in how providers experienced these social factors, as difficulties relating to connection with patients and the fatigue of working remotely were described by participants in this study who primarily worked remotely, providing services directly to patients' homes, compared to those who also provided some in-person services or who also used a hub-and-spoke model of telehealth. It may be that future use of telehealth will preferentially take place in a "hybrid" model, to allow for more interaction with colleagues and patients.

Participants also described limitations related to patients' access to and familiarity with the technology and high-speed Internet necessary to complete a telehealth appointment. These technology difficulties prevented appropriate physical examinations, leading to less buy-in from some medical geneticists, who ultimately found that they preferred in-person appointments. Furthermore, difficulty or inability to see patients during their telehealth appointments also limited providers' ability to assess patient emotions and understanding. Unsurprisingly, these limitations to physical examinations and psychosocial assessments have previously been described in the literature, in studies conducted prior to the COVID-19 pandemic (Cohen et al., 2016; Khan et al., 2021). Importantly, one participant described how physical exams are more easily performed using a hub-and-spoke model of telehealth, when compared to telehealth services provided directly to patients' homes. However, this provider also acknowledged that some patients cannot access satellite clinics where such hub-and-spoke appointments take place, which has also been described in the literature (Khan et al., 2021).

Given the many benefits of telehealth described previously, as well as the limitations to telehealth primarily affecting providers who exclusively provide services via telehealth or who provide such services preferentially to patients' homes, more institutions may adopt hybrid models in which their providers utilize multiple service delivery models, including telehealth to patients' homes, hub-and-spoke telehealth, and in-person appointments. Policies supporting the expansion and increased availability of high-speed broadband access will also become increasingly important, particularly for patients in rural areas, who may experience difficulty accessing in-person services or hub-and-spoke services via satellite clinics (Bauerly et al., 2019).

4.4.3 The Theme of External Factors

A number of external factors have dictated how alternative service delivery models could be used during and prior to the pandemic. Participants reported that in the past, billing issues such as payer policies limiting reimbursement for services provided via telehealth either limited their institution's use of telehealth or prohibited its use entirely. While some institutions prioritized expansion into telehealth in order to reach more patients, other for-profit systems did not invest in telehealth until patients could no longer be seen in-person due to the pandemic. Furthermore, only the hub-and-spoke model of telehealth could be used at a number of institutions, either because reimbursement policies required a clinical setting, or because licensure policies prevented providers from serving patients in their homes out-of-state. Some of these licensure and reimbursement issues affected genetic counselors differently than medical geneticists. In some of the states where participants are located, genetic counselors are not licensed. As a result of this lack of licensure, as well as because genetic counselors are not recognized as healthcare providers by CMS, a number of payers including Medicare do not cover genetic counselors' services unless they are billed "incident to" another healthcare provider such as a medical geneticist. The difficulties with licensure and reimbursement experienced by participants are unsurprising, given literature documenting similar issues (Bergstrom et al., 2021; Boothe et al., 2021; Cohen et al., 2016; Doyle et al., 2015; Khan et al., 2021; Shur et al., 2021).

Participants described how their practices were affected by a number of general licensure and reimbursement restrictions being "relaxed" during the pandemic, such that providers were able to care for patients out-of-state despite previous licensure restrictions, and telehealth services were more universally reimbursed by payers. However, some of the genetic counselors interviewed described how their use of telehealth was still shaped by payer policies. One participant, for example, described how they returned to clinic one day each week to accommodate payer policies requiring that they bill "incident to" a physician. Similarly, another study surveyed genetic counselors in the state of New York regarding changes to their practice during the COVID-19 pandemic, finding that there was no significant difference in how they billed for services during the pandemic (Bergstrom et al., 2021). In this study, several genetic counselor participants expressed the need for CMS recognition of genetic counselors, as well as for more widespread licensure of genetic counselors. Such measures would help remove barriers to the provision of both in-person and remote genetic counseling services.

In addition to expressing a desire for CMS recognition and licensure for genetic counselors in order to expand access to telegenetics services, participants also expressed uncertainty regarding how telehealth would be used in the future, concerned that when the emergency declaration is over, licensure and reimbursement restrictions affecting their use of telehealth may return in full force. One participant using telehealth directly to patients' homes expressed that this would prevent them from being able to provide services via telehealth at all, while another participant expressed that it would limit their use of telehealth to allow only the hub-and-spoke model, leaving many patients without access to genetics services. These new concerns about how impending restrictions could roll back advances in telegenetics do not yet appear to be described in the literature, and call for increased efforts from organizations such as NSGC to advocate for lasting changes to reimbursement and licensure policies to prevent such losses.

In addition to outside factors relating to billing and licensure, participants described help that they received from NYMAC, NSGC, genetic testing laboratories, and colleagues that helped to facilitate their transition to providing more services via telehealth, as well as resources that they would like to see in the future. These useful resources included conferences, training programs, educational material for patients regarding telehealth best practices, and funding for equipment necessary to expand a hub-and-spoke practice, while participants also mentioned desired resources such as policy updates, a program to help facilitate referrals or to reach patients as a private practice, and advocacy regarding the desired policy changes. This information will be helpful for NYMAC, other RGNs, professional organizations, and public health organizations to consider as possible avenues to support providers, as they work to increase access to genetics services.

4.4.4 The Theme of Evolving Models

The participants in this study represented a variety of experiences, with some regularly using a hub-and-spoke model of telehealth prior to the pandemic, some sparingly, and some providing services exclusively in-person. The beginning of the COVID-19 pandemic, coupled with new billing and reimbursement policies allowing for the provision of telehealth services directly to patients' homes, rapidly shifted the way these alternative service delivery models were used, as shown in this study and in others, with many genetics providers now providing telehealth services directly to patients' homes as a result (Pereira et al., 2020; Shur et al., 2021). Participants described how their service delivery models evolved throughout the pandemic, giving unique perspectives on changes in service delivery during the period from the spring of 2020 to the spring of 2021.

Prior to the pandemic, barriers such as limited space, limited equipment for use in hub-and-spoke telehealth, and problems relating to billing, reimbursement, and licensure prevented or limited the use of telehealth modalities for the majority of participants. As they shifted to online platforms at the beginning of the COVID-19 pandemic, some worked exclusively from home, and one adjusted their schedule to go to clinic in-person once per week to accommodate payer requirements for genetic counselors. This period of time involved a rapid process of training and troubleshooting, as has also been described by other publications (Aziz et al., 2020; Pereira et al., 2020; Shur et al., 2021). During this time, one participant reported seeing only urgent patients, while another who had previously provided services using a hub-and-spoke model described seeing fewer patients via hub-and-spoke and more patients via at-home telehealth.

As the pandemic continued, some participants were able to transition to seeing patients primarily in-person, some remained completely remote, and others described a hybrid model. One participant, who worked for an institution that contracted with other clinics to provide genetics services, reported having transitioned back and forth between completely online and primarily in-person a number of times in the past year, in response to COVID-19 case numbers in their area and individual clinics' preferences.

These unique perspectives illustrate the truly variable experiences of genetics providers within the NYMAC region, during the COVID-19 pandemic. Despite the many differences in how each participant and institution solved the problems presented during the public health emergency, each of the participants saw a role for telehealth in the future for their clinic. Some described the ideal future use on a patient-by-patient basis, meeting individuals' clinical and personal needs with the most appropriate service delivery model for their own situation, while others desired to remain fully remote following the close of the pandemic. Each of the participants described this future use as dependent upon changes to billing, reimbursement, and licensure policies, as previously described. In addition, some wished to expand their infrastructure for the hub-and-spoke model, dependent upon funding. One participant also described the possibility of new service delivery models in the future, such as using libraries to facilitate patients' access to their telehealth appointments, as has previously been described in the literature (DeGuzman et al., 2020). Indeed, the Western States Regional Genetics Network (WSRGN) has recently obtained funding to initiate such a project (Terry, June 4, 2021). While the future shape and use of telegenetics being dependent upon such external factors as funding, licensure, and billing is not a new idea (Bergstrom et al., 2021; Boothe et al., 2021; Cohen et al., 2016; Khan et al., 2021; Shur et al., 2021), the experiences of genetics providers providing telehealth services during the COVID-19 pandemic has not yet been described in much detail, and studies such as this one will be useful to establish providers' experiences and needs in the future.

4.4.5 The Theme of Provider Adaptation

In the course of interviews, participants described a number of ways in which they adapted to specific service delivery models, patients' medical and personal needs, and the needs of colleagues. Most commonly, participants described their use of flexibility to adapt to their new circumstances. This included anticipating or responding to patients' familiarity with technology, switching platforms when patients experienced technical difficulties, and becoming adept at determining which service delivery model would most efficiently deliver care to each patient given their clinical situation, distance from clinic, and other factors. By cultivating flexibility, the participants described, they were able to help reduce patient anxiety and remove or reduce barriers to accessing genetics services. Another study describing New York genetic counselors' service delivery during the COVID-19 pandemic similarly reported that the availability of telehealth allowed providers to be flexible in adapting to meet their patients' needs (Bergstrom et al., 2021). One of the participants in this current study also described offering information through additional modes of communication, to adjust to a lack of visual cues to assess patient understanding. This, too, has been previously described in the literature as a way that providers have adapted to provide services to their patients via telehealth (Cohen et al., 2016).

Perhaps more uniquely, participants in this study described adopting or further developing their own formal or informal roles as leaders as they worked to help themselves, their colleagues, their institutions, and clinics where they provided services on a contracted basis, adjust to the challenges presented by COVID-19. These leadership roles included a formal position on a steering committee; an informal expert in genetic counseling, as the only counselor at the health system; the go-to problem solver responsible for contract clinics; and an independent practitioner, responsible for setting up all necessary software and equipment. Other papers have described some of the set-up work involved in establishing new protocols and selecting and implementing the technology necessary to begin providing services via telehealth (Pereira et al., 2020), as well as the use of peer support systems and division meetings in establishing and troubleshooting problems for a new telehealth program (Shur et al., 2021), but this may be the first account of leadership taken on as an adaptive role by genetics providers in the transition to provide services via telehealth.

4.4.6 The Theme of Institutional Engagement

Participants described varying degrees of institutional engagement and support during the COVID-19 pandemic, as well as factors that helped them to initiate telehealth services in the context of little support or even opposition to telehealth from their institutions.

Some of the participants described supportive institutions that were actively engaged and receptive to their needs, keeping their providers in close communication, and eliciting their feedback and guidance throughout the process. This process of close communication and engagement appears to be similar to the regular institutional or departmental meetings used by some institutions that successfully and smoothly implemented telehealth services early in the pandemic, as described in the literature (Pereira et al., 2020; Shur et al., 2021). Some of the participants with actively engaged institutions described that their institutions had already begun implementing some telehealth services prior to the pandemic, and that during the pandemic, their institutions invested in equipment and/or IT support to facilitate their use of new telehealth platforms. This is significant, given a publication which suggested that existing telehealth infrastructure within the United States at the start of the COVID-19 pandemic was inadequate to address the current level of demand for telehealth services (Hong et al., 2020). Previous investment in telehealth knowledge and infrastructure, as well as continued investment during the COVID-19 pandemic, made these institutions better able to address the growing demands for telehealth services.

Other participants experienced less institutional engagement, or even active opposition, to their implementation of telehealth during the COVID-19 pandemic. Some received mixed messages about the importance of telehealth, in which the institution communicated that telehealth was a priority, but did not invest in it; some were given broad guidance and both the autonomy and responsibility to implement telehealth services independently; and some experienced pressure to return to clinic in-person. However, in the context of these differing levels of institutional engagement, a number of other factors helped to support participants in their transition to telehealth. Participants described support staff and colleagues as incredibly helpful during this period, which is consistent with telegenetics services described in other studies (Khan et al., 2021; Shur et al., 2021). Similarly, another study of genetic counselor perspectives prior to the COVID-19 pandemic described inadequate staffing of genetic counselors, physicians, and support staff as a major barrier to the implementation of an alternative service delivery model such as telehealth (Boothe et al., 2021). Other facilitators mentioned by participants in this study were technological upgrades – which, as previously described in terms of investment, seemed to be important in enabling the use of new models of telehealth during the pandemic (Hong et al., 2020).

4.4.7 Limitations

The goal of this study was to gain a richer understanding of the experiences of genetics providers within the NYMAC region as they transitioned to providing more services via telehealth during the COVID-19 pandemic, by interviewing providers with diverse experiences and perspectives. While this goal was met by interviewing five different providers with a variety of experiences, the study is limited in that it likely did not reach theoretical saturation, or the point at which no further themes or new ideas can be identified through conducting additional interviews (Guest, Bunce, & Johnson, 2016), because new codes continued to be identified in each interview.

Because the interviewees were all members of the NYMAC Telegenetics Community of Practice, selection bias is a possible limitation of this study, in which perhaps participants with a greater degree of prior experience with telegenetics were preferentially included in the study. However, TCOP leadership made every effort to invite providers with varying degrees of experience. Furthermore, in a qualitative study with a small sample size, the goal is not to have a representative sample, but rather, to capture a variety of different perspectives.

Thematic analysis of qualitative data is a subjective process, in which the researcher's interests and values are inextricable from the analysis and conclusions. The lead researcher in this study is a new genetic counseling graduate with prior experience working for NYMAC, whose values include the importance of increasing access to genetics services. To ensure the appropriateness of coding and the later formation of themes, a member of the Committee performed an audit of the first three coded transcripts, identifying additional concepts that the researcher then created new codes to capture. Additionally, the themes were formed and revised in conversation with members of the Committee to capture the most important elements of the data.

4.4.8 Future Directions

Throughout the interviews, participants described how their patients and institutions responded to telehealth during the COVID-19 pandemic, as well as how various aspects of the transition affected these parties. Additional studies may investigate clinical outcomes for patients seen via telegenetics in comparison to patients seen in-person, the benefits and limitations of telegenetics for patients and administrative personnel during and after the COVID-19 pandemic, as well as what interest, unique barriers, and needs these groups may have relating to telegenetics. Further, this study describes providers' expectations and hopes for the future use of telehealth, as well as factors that may influence the ways that telehealth is used in the future. Therefore, future studies examining provider experiences and needs surrounding their use of telegenetics as it continues to evolve will also be important.

In this study, participants also described resources that would be helpful to them in the future, to help facilitate their use of telegenetics. Anecdotally, public health professionals have described duplications of effort by different public health organizations, as well as a wealth of publicly available resources that may be seldom accessed by genetics providers who could make use of them. A study of the utilization of some key resources mentioned by participants in this study may be revealing, and may help organizations more effectively allocate their resources.

4.5 Conclusions

Participants in this study had diverse experiences adapting to the COVID-19 pandemic, informed by factors such as their prior experiences with telehealth, their practice setting, their patient population, and their chosen service delivery models during this time. Despite these diverse experiences, each participant described a role for telehealth in their future practice, to allow for the flexibility necessary to meet diverse patients' needs and ensure broader access to genetics services. Furthermore, participants described policy actions and desired support from NYMAC – including

CMS recognition of genetic counselors, permanently increased flexibility in licensure requirements and reimbursement policies for providers serving patients via telehealth, and funding support for growing telehealth programs – that would help to facilitate this ideal future use.

5.0 Research Significance to Genetic Counseling and Public Health

This survey and interview project sought to describe barriers to the provision of telegenetics services during the COVID-19 pandemic, the perceived value and demand for telegenetics services during this time period, and what resources or policy changes may be necessary to continue providing such services into the future. In other words, the goal of this work is to learn from the dramatic increase in telehealth service provision that took place during this tumultuous time. The fulfillment of these goals has significance for the genetic counseling profession and for the advancement of public health, as will be discussed in terms of the CDC's 10 Essential Public Health Services (EPHS) and the goals of the NYMAC Regional Genetics Network.

This study helped to quantify the change in genetics service delivery that occurred during the pandemic. When asked about the proportion of patients seen using different service delivery models prior to the pandemic, respondents reported that they saw 88% of their patients in a traditional in-person setting, 8% via phone consultation, 3% through live video visits. During the pandemic, these numbers drastically shifted to 16% of patients seen in-person, 60% through live video visits, and 23% over the phone. Furthermore, nearly 60% of respondents reported that they would continue to offer services via telehealth modalities in the future. These results reveal a service delivery landscape very different from the models that most genetic counselors focused on during their academic training. Indeed, in interviews, participants described difficulties in striking a balance in telehealth versus in-person cases for the students they were training. In addition, participants described a number of ways that they had adapted to provide services remotely, including developing additional communication strategies to ensure their patients' understanding.

Such service delivery shifts, on-the-job adaptations, and clinical training quandaries suggest the need for genetic counseling programs to adjust their training programs to incorporate newly emerging best practices such as those described by the participants, so that the field can meet new service delivery challenges. In addition to adapting genetic counseling training programs, continuing education programs may be used to deliver this important information to already practicing genetics professionals.

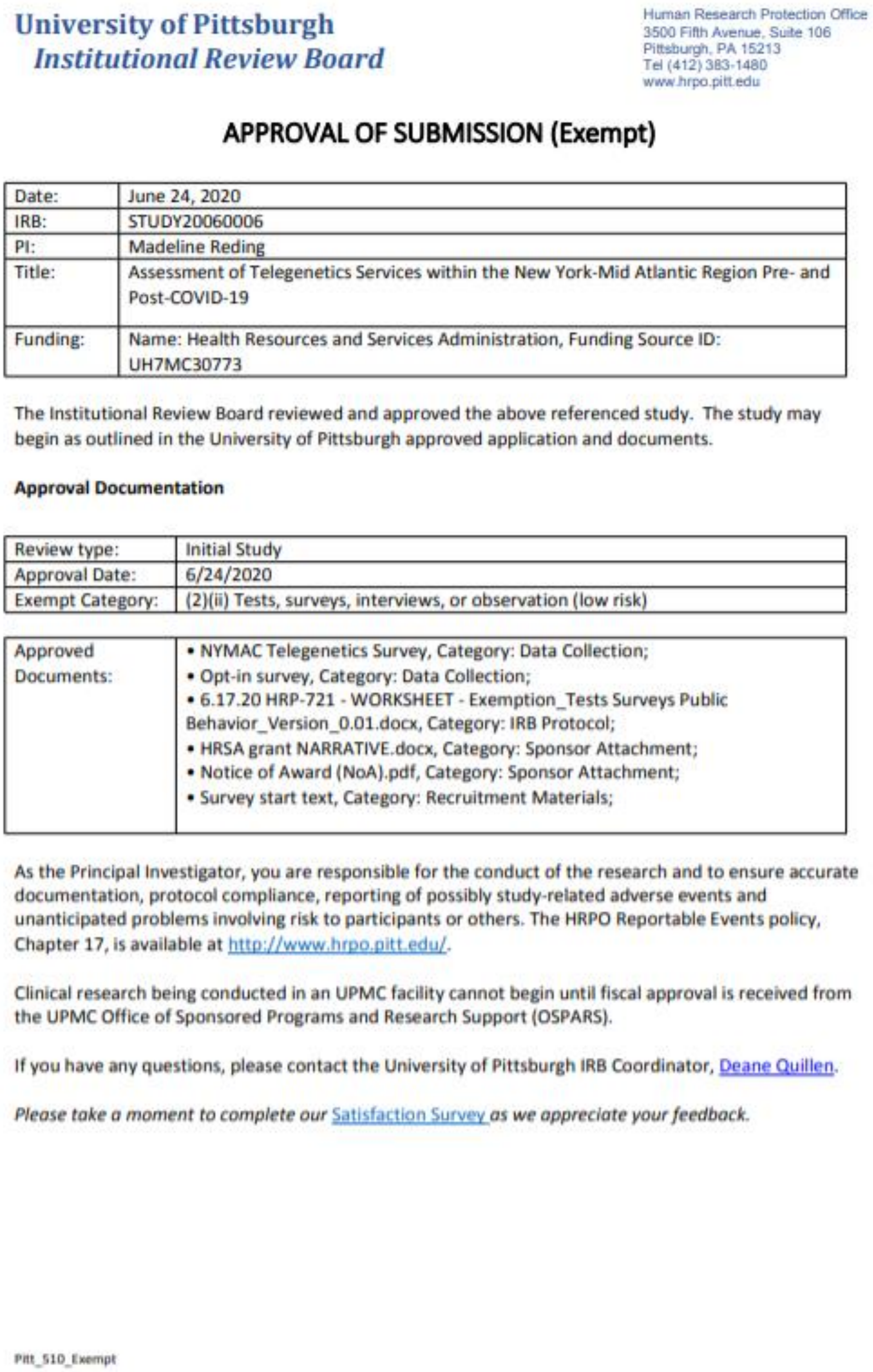
This study was conducted in partnership with the NYMAC Regional Genetics Network, in support of its goals to “Support a regional infrastructure for genetic services” and “Facilitate the use of telehealth in genetics” (NYMAC, n.d.-b). The survey elicited resources that participants thought would be helpful to them to continue providing services via telehealth – most prominently, help with billing and reimbursement, policy issues including licensure, telehealth laws, and consent, and resources for their patients to facilitate their use of telegenetics services. By identifying areas where providers need additional support, the project has helped NYMAC to identify areas to focus their efforts. Furthermore, this partnership supports the EPHS function to “Strengthen, support, and mobilize communities and partnerships to improve health” (CDC, 2020). By eliciting desired resources from participants and reporting areas of need to NYMAC so that it can focus its efforts, the project functions to facilitate and strengthen the partnership between NYMAC and the providers it supports within the region.

As previously mentioned, the survey of genetics providers within the NYMAC region revealed that help with policy issues including licensure, telehealth laws, and consent was one of the most commonly selected areas in which respondents wanted NYMAC assistance. In addition, the interviews revealed a number of policy issues that could impact participants’ use of telehealth in the future. Participants desired CMS recognition of genetic counselors to facilitate the provision of genetic counselor services in-person and via telehealth, without the restriction of direct physician supervision; state licensure for genetic counselors, to facilitate reimbursement for genetic counselor services by non-CMS payers; permanent changes to out-of-state licensure restrictions, to allow out-of-state patients to access genetics services via telehealth without having to travel; and permanent changes to reimbursement policies, to allow reimbursement for services provided via telehealth modalities. Though NYMAC cannot advocate for policy as a federal grantee (Terry, June 4, 2021), this project brings attention to some providers' desired policy changes and the ways in which they would impact telegenetics providers. With this information, other organizations such as the NSGC may advocate for such policy changes, supporting the EPHS function to "Create, champion, and implement policies, plans, and laws that impact health" (CDC, 2020).

While the participants described that the continued availability of telegenetics services is dependent upon such policy issues – and indeed, in the telegenetics survey, as many as 33% of respondents were unsure if they would be able to continue offering telegenetics services – they also described the potential benefits to their patients. If providers and institutions are able to continue offering telegenetics services in the future, patients who live prohibitively far from clinic or who have other situations that would prevent them from traveling to clinic would still be able to access genetics services. If not, then a number of patients would lose access to these necessary services. The information gathered by this project regarding needed resources, policy changes, the potential effects of inaction, therefore also work toward the EPHS function to "Assure an effective system that enables equitable access to the individual services and care needed to be healthy" (CDC, 2020).

In summary, this study has significance for genetic counseling, as it provides additional information about current uses of service delivery models, which may be used to tailor genetic counselor training programs and continuing education for genetic counselors. The study also has significance for public health, supporting NYMAC goals of increasing access to genetics services through telegenetics and revealing areas in which additional assistance and policy changes are needed in order to support the continued use of telegenetics and ensure broader access to genetics services in the future.

Appendix A Institutional Review Board Approval



University of Pittsburgh
Institutional Review Board

Human Research Protection Office
3500 Fifth Avenue, Suite 106
Pittsburgh, PA 15213
Tel (412) 383-1480
www.hrpo.pitt.edu

APPROVAL OF SUBMISSION (Exempt)

Date:	June 24, 2020
IRB:	STUDY20060006
PI:	Madeline Reding
Title:	Assessment of Telegenetics Services within the New York-Mid Atlantic Region Pre- and Post-COVID-19
Funding:	Name: Health Resources and Services Administration, Funding Source ID: UH7MC30773

The Institutional Review Board reviewed and approved the above referenced study. The study may begin as outlined in the University of Pittsburgh approved application and documents.

Approval Documentation

Review type:	Initial Study
Approval Date:	6/24/2020
Exempt Category:	(2)(ii) Tests, surveys, interviews, or observation (low risk)

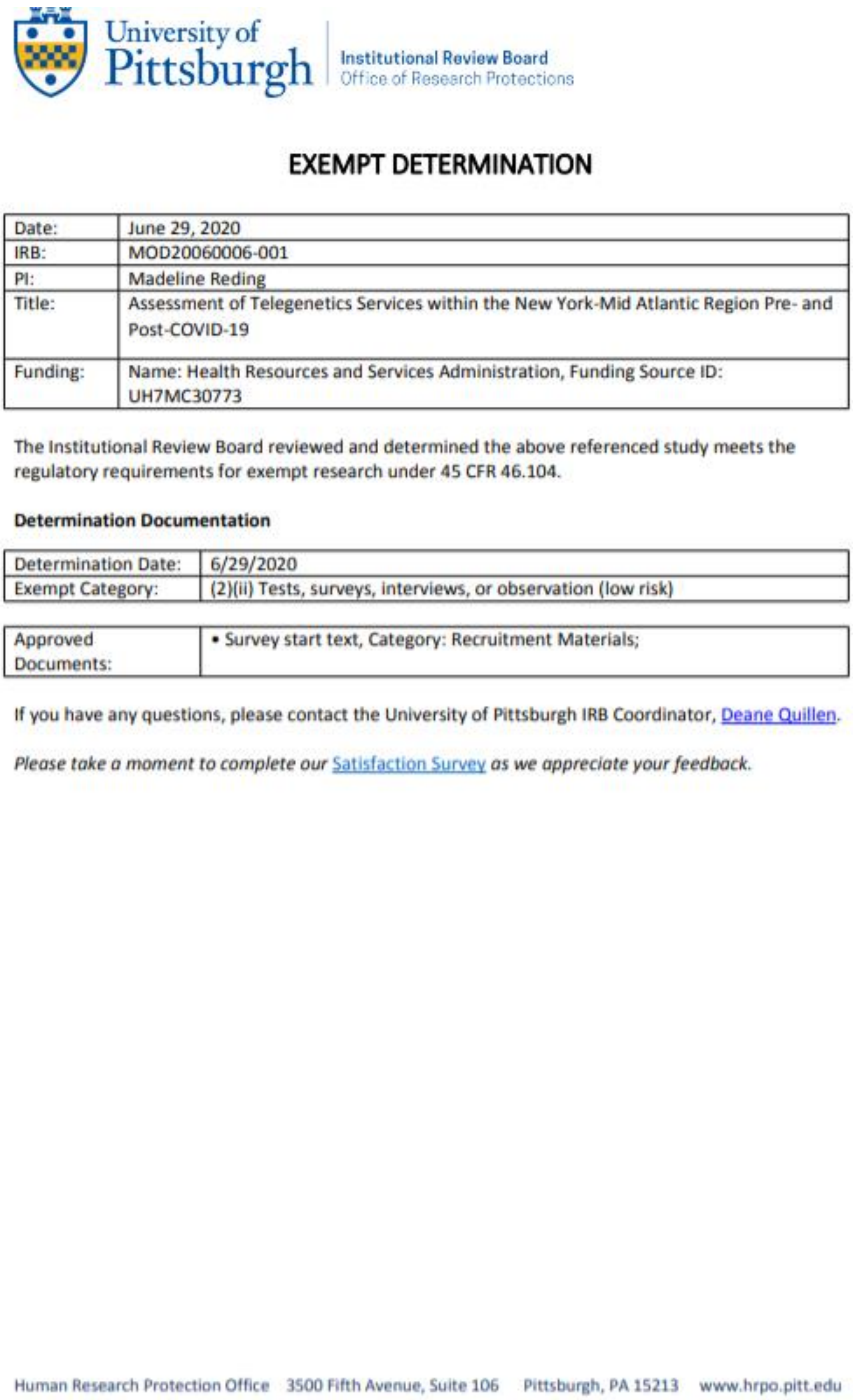
Approved Documents:	• NYMAC Telegenetics Survey, Category: Data Collection; • Opt-in survey, Category: Data Collection; • 6.17.20 HRP-721 - WORKSHEET - Exemption_Tests Surveys Public Behavior_Version_0.01.docx, Category: IRB Protocol; • HRSA grant NARRATIVE.docx, Category: Sponsor Attachment; • Notice of Award (NoA).pdf, Category: Sponsor Attachment; • Survey start text, Category: Recruitment Materials;

As the Principal Investigator, you are responsible for the conduct of the research and to ensure accurate documentation, protocol compliance, reporting of possibly study-related adverse events and unanticipated problems involving risk to participants or others. The HRPO Reportable Events policy, Chapter 17, is available at http://www.hrpo.pitt.edu/.

Clinical research being conducted in an UPMC facility cannot begin until fiscal approval is received from the UPMC Office of Sponsored Programs and Research Support (OSPARS).

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, Deane Quillen.

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



University of Pittsburgh | Institutional Review Board
Office of Research Protections

EXEMPT DETERMINATION

Date:	June 29, 2020
IRB:	MOD20060006-001
PI:	Madeline Reding
Title:	Assessment of Telegenetics Services within the New York-Mid Atlantic Region Pre- and Post-COVID-19
Funding:	Name: Health Resources and Services Administration, Funding Source ID: UH7MC30773

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

Determination Documentation

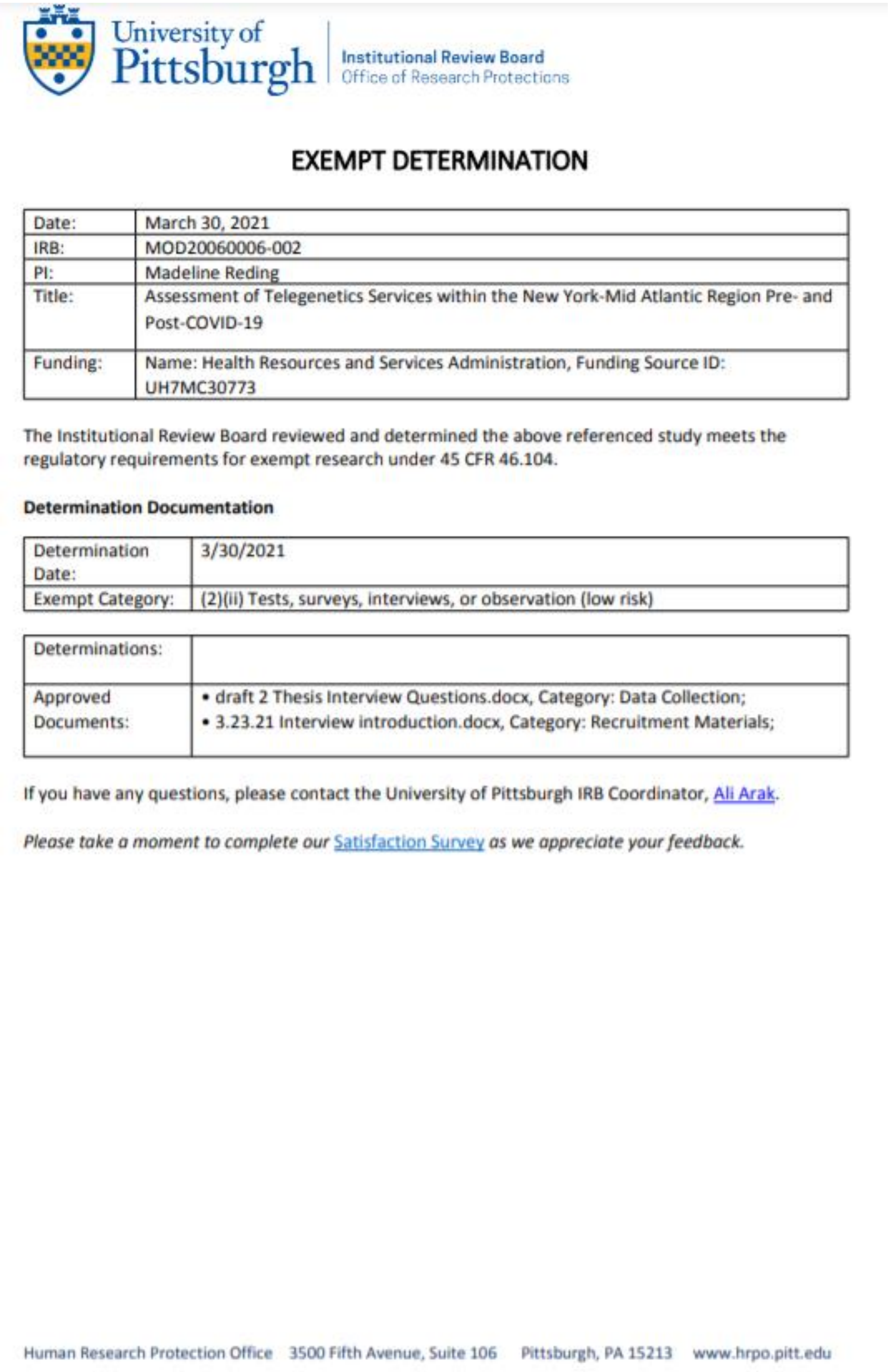
Determination Date:	6/29/2020
Exempt Category:	(2)(ii) Tests, surveys, interviews, or observation (low risk)

Approved Documents:	• Survey start text, Category: Recruitment Materials;

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, Deane Quillen.

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

Human Research Protection Office 3500 Fifth Avenue, Suite 106 Pittsburgh, PA 15213 www.hrpo.pitt.edu



University of Pittsburgh | **Institutional Review Board**
Office of Research Protections

EXEMPT DETERMINATION

Date:	March 30, 2021
IRB:	MOD20060006-002
PI:	Madeline Reding
Title:	Assessment of Telegenetics Services within the New York-Mid Atlantic Region Pre- and Post-COVID-19
Funding:	Name: Health Resources and Services Administration, Funding Source ID: UH7MC30773

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

Determination Documentation

Determination Date:	3/30/2021
Exempt Category:	(2)(ii) Tests, surveys, interviews, or observation (low risk)

Determinations:	
Approved Documents:	• draft 2 Thesis Interview Questions.docx, Category: Data Collection; • 3.23.21 Interview introduction.docx, Category: Recruitment Materials;

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

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

Human Research Protection Office 3500 Fifth Avenue, Suite 106 Pittsburgh, PA 15213 www.hrpo.pitt.edu

Appendix B Survey Text

Appendix B.1 Qualtrics Introductory Text

Thank you for participating in this research through the University of Pittsburgh. We are asking you to participate in this survey because you are a genetics professional practicing in the NYMAC region (Delaware, the District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, the Virgin Islands, Virginia, and West Virginia). NYMAC is one of seven regional genetics networks in the country funded by the Genetic Services Branch in the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau. Your responses will inform NYMAC about how your practice is adapting to deliver patient care during the COVID-19 public health emergency, and what has helped and hindered that process. Your input will help NYMAC develop needed resources and deploy available funding to support genetics providers and families toward the overall goal of improving access to genetic services throughout the region.

We estimate the survey will take less than 10 minutes to complete. All answers will be kept confidential. Please know that your participation in this effort is completely voluntary. You may choose not to answer some or all of the questions posed, and you may withdraw at any time. There are no personal benefits or compensation for participating, and the only foreseeable risk is breach of confidentiality. The information learned from this project will be shared within the NYMAC group and, in aggregate form only, at meetings and in publications. We will maintain your privacy by storing this data in a secure cloud drive, and by de-identifying data before sharing it outside of the study team. You will also have the option to provide your email address if you wish to receive telegenetics assistance, or if you wish to be contacted for further related research by this study team. If you choose to do so, your email address will be collected in a separate survey and will not be linked to or stored with your responses below.

Please answer all questions as they apply to your clinic as a whole. If you work at more than one clinic, please consider just one clinic each time you submit a survey response. This will help us to avoid duplications in our data.

If you have questions or concerns, please contact Madeline Reding (MQR2@pitt.edu) or Andrea Durst (ADurst@pitt.edu).

Appendix B.2 NYMAC

Telegenetics Survey

Please indicate if your clinical practice is located in any the following areas. (CHECK ALL THAT APPLY)

- ☐ Delaware (1)
- ☐ District of Columbia (2)
- ☐ Maryland (3)
- ☐ New Jersey (4)
- ☐ New York (5)
- ☐ Pennsylvania (6)
- ☐ Puerto Rico (7)
- ☐ Virgin Islands (8)
- ☐ Virginia (9)
- ☐ West Virginia (10)
- ☐ None of the above (11)

Skip To: End of Survey If Please indicate if your clinical practice is located in any the following areas. (CHECK ALL THAT... = None of the above

What is the ZIP code of your primary clinic?

____

What is the name of your clinic or institution?

____

Which of the following best describes your practice size? Note: "Clinician" may indicate MD, DO, GC, NP, PA, etc.

- ○ Solo practice (1)
- ○ 2-5 clinicians (2)
- ○ 6-10 clinicians (3)
- ○ 11-15 clinicians (4)
- ○ 16 or more clinicians (5)

Which of the following best describes your practice? (CHECK ALL THAT APPLY)

☐ Clinician-owned solo or group practice (1)

☐ Hospital/health system owned (2)

☐ Health maintenance organization (e.g. Kaiser Permanente) (3)

☐ Federally Qualified Health Center or similar (4)

☐ Non-federal government clinic (e.g. state, county, city, public health clinic, etc.) (5)

☐ Academic health center/faculty practice (6)

☐ Federal (Military, Veterans Administration, Department of Defense) (7)

☐ Rural Health Clinic (8)

☐ Indian Health Service (9)

☐ Laboratory (10)

☐ Private business (11)

☐ Other (please specify): (12)

____

Which of the following describes your practice's genetics specialty area? (CHECK ALL THAT APPLY)

☐ Adult (1)

☐ Cancer (2)

☐ Cardiovascular genetics (3)

☐ General (4)

☐ Metabolic (5)

☐ Neurogenetics (6)

☐ Pediatric (7)

☐ Prenatal (8)

☐ Reproductive (9)

☐ Other (please specify): (10) ____________________

Which of the following professionals provide genetic services at your clinic? (CHECK ALL THAT APPLY)

☐ MD geneticist (1)

☐ PhD geneticist (2)

☐ Genetic counselor (3)

☐ Genetics nurse (4)

☐ Dietitian (5)

☐ Other (please specify): (6) ____

✱

There are a variety of telemedicine modalities, including live video visits, telephone consultations, and the not-in-real-time sending and reviewing of patient information such as pictures or vital signs by email, text, patient portal, etc. (store-and-forward).

Please estimate the percent of patients seen at your clinic using each of the following modalities, BEFORE the COVID-19 public health emergency. (Total must equal 100%.)
________ In-person consultation (1)
________ Live video visits (2)
________ Phone consultation with patient (3)
________ Store-and-forward (4)
________ Other (5)

Carry Forward All Choices - Displayed & Hidden from "There are a variety of telemedicine modalities, including live video visits, telephone consultations, and the not-in-real-time sending and reviewing of patient information such as pictures or vital signs by email, text, patient portal, etc. (store-and-forward). Please estimate the percent of patients seen at your clinic using each of the following modalities, BEFORE the COVID-19 public health emergency. (Total must equal 100%.)"

✱ X→

There are a variety of telemedicine modalities, including live video visits, telephone consultations, and the not-in-real-time sending and reviewing of patient information such as pictures or vital signs by email, text, patient portal,etc. (store-and-forward).

Please estimate the percent of patients seen at your clinic using each of the following modalities DURING the COVID-19 public health emergency. (Total must equal 100%.)

_______ In-person consultation (1)
_______ Live video visits (2)
_______ Phone consultation with patient (3)
_______ Store-and-forward (4)
_______ Other (5)

Skip To: Q11 If Condition: Live video visits Is Equal to 0. Skip To: Is your clinic planning to provide ge....

Skip To: Q14 If Condition: Phone consultation with pat... Is Equal to 0. Skip To: Is your clinic planning to provide ge....

Display This Question:

If If There are a variety of telemedicine modalities, including live video visits, telephone consultati... Live video visits Is Equal to 0

Is your clinic planning to provide genetic services by live video visits in response to the COVID-19 public health emergency?

○ Yes (1)

○ No (2)

○ Unsure (3)

Skip To: Q12 If Is your clinic planning to provide genetic services by live video visits in response to the COVID... = No

Skip To: Q13 If Is your clinic planning to provide genetic services by live video visits in response to the COVID... = Yes

Display This Question:

If Is your clinic planning to provide genetic services by live video visits in response to the COVID... = No

Can you tell us why your clinic won't be providing genetic services by live video visits? (CHECK ALL THAT APPLY)

- ☐ Concerns about technology limiting psychosocial care or education of patients (1)
- ☐ Logistical issues: medical records, coordinating testing (2)
- ☐ Technology issues at the patient site (3)
- ☐ Technology issues at the genetics provider's site (4)
- ☐ Engagement or efficiency at the patient site (5)
- ☐ Licensure, laws, liability (6)
- ☐ Care coordination and patient follow-up (7)
- ☐ Institutional organization, staffing, getting started (8)
- ☐ Credentialing issues (9)
- ☐ Billing and finances (10)
- ☐ Other (please specify): (11) ____

Display This Question:

If Is your clinic planning to provide genetic services by live video visits in response to the COVID... = Yes

Can you tell us when your clinic plans to start providing genetic services by live video?

○ within 1 month (1)

○ within 2 months (2)

○ within 3 months (3)

○ more than 3 months (4)

Display This Question:

If If There are a variety of telemedicine modalities, including live video visits, telephone consultati... Phone consultation with patient Is Equal to 0

Is your clinic planning to provide genetic services via telephone consultations with patients in response to the COVID-19 public health emergency?

○ Yes (1)

○ No (2)

○ Unsure (3)

Skip To: Q15 If Is your clinic planning to provide genetic services via telephone consultations with patients in... = No

Skip To: Q16 If Is your clinic planning to provide genetic services via telephone consultations with patients in... = Yes

---

Display This Question:

If Is your clinic planning to provide genetic services via telephone consultations with patients in... = No

Carry Forward All Choices - Entered Text from "Can you tell us why your clinic won't be providing genetic services by live video visits? (CHECK ALL THAT APPLY)"

X→

Can you tell us why your clinic won't be providing genetic services via telephone consultations with patients? (CHECK ALL THAT APPLY)

☐ Concerns about technology limiting psychosocial care or education of patients (1)

☐ Logistical issues: medical records, coordinating testing (2)

☐ Technology issues at the patient site (3)

☐ Technology issues at the genetics provider's site (4)

☐ Engagement or efficiency at the patient site (5)

☐ Licensure, laws, liability (6)

☐ Care coordination and patient follow-up (7)

☐ Institutional organization, staffing, getting started (8)

☐ Credentialing issues (9)

☐ Billing and finances (10)

☐ Other (please specify): (11)

Display This Question:

If Is your clinic planning to provide genetic services via telephone consultations with patients in... = Yes

Carry Forward All Choices - Displayed & Hidden from "Can you tell us when your clinic plans to start providing genetic services by live video?"

Can you tell us when your clinic plans to start offering genetic services via telephone consultations with patients?

○ within 1 month (1)

○ within 2 months (2)

○ within 3 months (3)

○ more than 3 months (4)

What types of patients did your clinic see by these modalities of telegenetics, BEFORE and DURING the COVID-19 public health emergency? (CHECK ALL THAT APPLY)

	BEFORE COVID-19 Video (1)	BEFORE COVID-19 Telephone (2)	BEFORE COVID-19 Store-and-forward (3)	DURING COVID-19 Video (4)	DURING COVID-19 Telephone (5)	DURING COVID-19 Store-and-forward (6)
New patients (1)	☐	☐	☐	☐	☐	☐
Follow-up patients (2)	☐	☐	☐	☐	☐	☐
Other (please specify): (3)	☐	☐	☐	☐	☐	☐

What services did your clinic provide by these modalities of telegenetics, BEFORE and DURING the COVID-19 public health emergency? Note: MD services are defined as evaluation and management services. (PLEASE CHECK ALL THAT APPLY)

	BEFORE COVID-19 Video (1)	BEFORE COVID-19 Telephone (2)	BEFORE COVID-19 Store-and-forward (3)	DURING COVID-19 Video (4)	DURING COVID-19 Telephone (5)	DURING COVID-19 Store-and-forward (6)
Prenatal genetic counseling (1)	☐	☐	☐	☐	☐	☐
Prenatal MD genetic services (2)	☐	☐	☐	☐	☐	☐
Pediatric genetic counseling (3)	☐	☐	☐	☐	☐	☐
Pediatric MD genetic services (4)	☐	☐	☐	☐	☐	☐
Adult genetic counseling (5)	☐	☐	☐	☐	☐	☐
Adult MD genetic services (6)	☐	☐	☐	☐	☐	☐
Genetic results reporting (7)	☐	☐	☐	☐	☐	☐
Other (please specify): (8)	☐	☐	☐	☐	☐	☐

Which of the following have changed at your clinic since the COVID-19 public health emergency? (PLEASE CHECK ALL THAT APPLY)

- ☐ Fewer overall patients receiving services (1)
- ☐ More patients receiving services (2)
- ☐ Fewer patient referrals (3)
- ☐ More patients requesting telehealth (4)
- ☐ Telehealth offered to more types of patients (5)
- ☐ Modified clinic hours (6)
- ☐ Fewer providers available (7)
- ☐ Longer wait times (8)
- ☐ Shorter wait times (9)
- ☐ All patients have better access to genetics services (10)
- ☐ Only some patients have better access to genetics services (11)
- ☐ Other (please specify): (12) ____

Skip To: Q42 If Which of the following have changed at your clinic since the COVID-19 public health emergency? (P... = Only some patients have better access to genetics services

Display This Question:

If Which of the following have changed at your clinic since the COVID-19 public health emergency? (P... = Only some patients have better access to genetics services

Please describe which sub-populations have experienced more challenges to utilizing telegenetics services.

____

What were/are the top BARRIERS for PROVIDERS to utilizing telegenetics, before and during the COVID-19 public health emergency? Please choose the top 3 for each time period.

	BEFORE COVID-19 (1)	DURING COVID-19 (2)
Lack of institutional support (1)	☐	☐
Lack of provider time (2)	☐	☐
Lack of provider interest (3)	☐	☐
Lack of patient interest or demand (4)	☐	☐
Lack of necessary staff (5)	☐	☐
Concerns about telegenetics limiting psychosocial care or education of patients (6)	☐	☐
Workflow and logistical issues (sample collection, obtaining medical records) (7)	☐	☐
Lack of appropriate technology (8)	☐	☐
Inadequate funding, billing, and reimbursement (9)	☐	☐
Trouble coordinating with other clinics where the patients would be located during telegenetics sessions (10)	☐	☐
Licensure and legal issues (11)	☐	☐
Concerns about appropriate care coordination and follow up (12)	☐	☐
Issues with needed credentialing (13)	☐	☐

Lack of experience and training about telehealth (14)	☐	☐
Adequate patient access to existing in-person genetic services (15)	☐	☐
Other (please specify): (16)	☐	☐
Does not apply (17)	☐	☐

What were/are the top FACILITATORS for PROVIDERS for utilizing telegenetics, before and during the COVID-19 public health emergency? Please choose the top 3 for each time period.

	BEFORE COVID-19 (1)	DURING COVID-19 (2)
Institutional support (1)	☐	☐
Available provider time (2)	☐	☐
Provider interest (3)	☐	☐
Patient interest and demand (4)	☐	☐
Availability of other necessary staff (5)	☐	☐
Solutions for workflow and logistical issues (sample collection, obtaining medical records) (6)	☐	☐
Availability of appropriate technology (7)	☐	☐
Adequate funding, billing, and reimbursement (8)	☐	☐
Manageable licensure and legal issues (9)	☐	☐
Solutions for care coordination and follow up (10)	☐	☐
Available credentialing as needed (11)	☐	☐
Lack of available in-person genetic services (12)	☐	☐
Training or other assistance from NYMAC (13)	☐	☐
Other (please specify): (14)	☐	☐

Does not apply (15)	☐	☐

What were/are the top BARRIERS for PATIENTS to the utilization of telegenetics, before and during the COVID-19 public health emergency? Please choose the top 3 for each time period.

	BEFORE COVID-19 (1)	DURING COVID-19 (2)
Lack of awareness of telehealth (1)	☐	☐
Lack of available telehealth services (2)	☐	☐
Lack of patient interest (3)	☐	☐
Concerns about telegenetics limiting psychosocial care or education (4)	☐	☐
Concerns about telegenetics limiting appropriate medical evaluation (5)	☐	☐
Lack of appropriate technology (6)	☐	☐
Lack of Internet coverage (7)	☐	☐
Inadequate insurance coverage (8)	☐	☐
Lack of experience with telehealth (9)	☐	☐
Adequate access to in-person genetic services (10)	☐	☐
Other (please specify): (11)	☐	☐
Does not apply (12)	☐	☐

What were/are the top FACILITATORS for PATIENTS for utilizing telegenetics, before and during the COVID-19 public health emergency? Please choose the top 3 for each time period.

	BEFORE COVID-19 (1)	DURING COVID-19 (2)
Expanded options for telegenetic services (1)	☐	☐
Experience with telehealth (2)	☐	☐
Awareness of telehealth (3)	☐	☐
Adequate payment/insurance coverage (4)	☐	☐
Availability of appropriate technology (5)	☐	☐
Adequate Internet coverage (6)	☐	☐
Convenience (7)	☐	☐
Lack of access to in-person genetic services (8)	☐	☐
Other (please specify): (9)	☐	☐
Does not apply (10)	☐	☐

Please think of the support and resources you receive from your institution that help you be effective in providing genetic services through telemedicine. To what extent do you agree with the following:

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	Don't know (5)	N/A (6)
I have the resources necessary to practice telemedicine. (1)	○	○	○	○	○	○
I have the knowledge necessary to practice telemedicine. (2)	○	○	○	○	○	○
A specific person or group is available to assist me with system difficulties. (3)	○	○	○	○	○	○
My clinic's efforts to reconfigure the workflow and resources to integrate telemedicine was significant. (4)	○	○	○	○	○	○
Senior management in my clinic has been helpful in implementing telemedicine. (5)	○	○	○	○	○	○

In general, my organization has supported the use of telemedicine. (6)	○	○	○	○	○	○

Does your clinic plan to continue offering services through alternative models after the COVID-19 public health emergency subsides? Please explain.

○ Yes (4) ____

○ Maybe (5) ____

○ No (6) ____

Have you or others in your clinic used any NYMAC or other Regional Genetics Network resources to support your use of these telegenetics modalities? (CHECK ALL THAT APPLY)

☐ One-on-one support for telegenetics utilization (1)

☐ Virtual or in-person telegenetics training (2)

☐ NYMAC Telegenetics Community of Practice conference calls and/or webinars (3)

☐ NYMAC funding (4)

☐ Other (please specify): (5)

____

☐ None (6)

Does your clinic have need for technical assistance or support for your telegenetics services? If yes, which services might be useful for your clinic? (CHECK ALL THAT APPLY)

☐ Provider training in telegenetics (1)

☐ Telemedicine equipment (2)

☐ Resources for patients to use telegenetics (3)

☐ Device and platform selection (4)

☐ Billing and reimbursement (5)

☐ Policy issues including licensure, telehealth laws, and consent (6)

☐ Evaluation (7)

☐ Other (please specify): (8) ____

☐ No assistance or support needed (9)

Would you like to receive future communications about one-on-one support for telegenetics utilization or future trainings for telegenetics, and/or would you be willing to participate in an interview to assess telegenetics utilization?

If you would like to participate in either of these opportunities, please follow this link to provide your email address in a separate survey.

Appendix B.3 Opt-In to Telegenetics Assistance or Interview Survey

Which of the following would you be interested in? (CHECK ALL THAT APPLY)

☐ Existing NYMAC telegenetics resources (1)

☐ Future trainings for telegenetics (2)

☐ Participating in an interview to further assess your experience with telegenetics (3)

Prior to the COVID-19 public health emergency, how often did you provide genetics services via telegenetics modalities (live video visits, telephone consultations, store-and-forward, etc.)?

○ Always (1)

○ Most of the time (2)

○ About half the time (3)

○ Sometimes (4)

○ Never (5)

---

*

Please enter your email address.

____

Appendix C Interview Script

Appendix C.1 Introductory Text

Hello ____,

We are reaching out to you as a member of the NYMAC Telegenetics Community of Practice (TCOP) to invite you to participate in an interview regarding your use of telehealth modalities as a genetics provider during the COVID-19 public health emergency. We are asking you to participate in this interview because you are a genetics professional practicing in the NYMAC region (Delaware, the District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, the Virgin Islands, Virginia, and West Virginia).

NYMAC is one of seven regional genetics networks in the country funded by the Genetic Services Branch in the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau. This research through the University of Pittsburgh will help inform NYMAC about how providers are adapting to deliver patient care during the COVID-19 public health emergency, and what has helped and hindered that process. Your input will help NYMAC develop needed resources and deploy available funding to support genetics providers and families toward the overall goal of improving access to genetic services throughout the region. In addition, this information will also be used for a master’s level thesis project for Madeline Reding, a graduate student in genetic counseling and public health genetics.

We estimate the interview will take approximately 30 minutes to complete. The interview will be audio- and video-recorded via Zoom. All answers will be kept confidential. Please know that your participation in this effort is completely voluntary. You may choose not to answer some or all of the questions posed, and you may withdraw at any time. There are no personal benefits or compensation for participating, and the only foreseeable risk is breach of confidentiality. The information learned from this project will be shared within the NYMAC group and, in aggregate form only, at meetings and in publications. We will maintain your privacy by storing this data in a secure cloud drive, and by de-identifying data before sharing it outside of the study team.

If you have questions or concerns, please contact Madeline Reding (MQR2@pitt.edu) or Andrea Durst (ADurst@pitt.edu).

Appendix C.2 Interview Questions

Appendix C.2.1 Introductory Questions

1. What is your profession?
2. How many years have you practiced?
3. What is your clinical specialty area? For example: pediatrics, prenatal, cancer genetics.
4. What state or territory is your practice located in?
5. To what extent do you work with medically underserved populations in your clinical practice?
6. Please describe how you used telehealth modalities to provide care to patients prior to the COVID-19 pandemic. For the purposes of this conversation, this includes phone consultations, live video visits, and store-and-forward, which is the not-in-real-time

sending and reviewing of patient information such as pictures or vital signs by email, text, patient portal, etc.

7. Did your use of these telehealth modalities change after the beginning of the pandemic, and if so, in what ways?
8. How did your patients respond to telehealth services during the pandemic?
9. How about your institution?
10. How do you feel about providing services via telehealth, and did that change during the pandemic?

Appendix C.2.2 Questions about Facilitating Factors

1. Before the beginning of the pandemic, what factors helped to facilitate your use of telehealth? Or, if you weren’t yet using telehealth modalities, what factors, if any, suggested a need for telehealth or drew you to telehealth?
    a. In what ways, and to what extent, did your institution respond to these factors?
    b. In what ways, and to what extent, did outside organizations respond to those factors in a way that affected your practice?
2. What were the most significant factors facilitating your use of telehealth, after the beginning of the pandemic?
    a. In what ways, and to what extent, did your institution respond to these factors?
    b. In what ways, and to what extent, did outside organizations respond to those factors in a way that affected your practice?

Appendix C.2.3 Questions about Barriers

1. What were the most significant challenges to providing services via telehealth before the pandemic, for you?
    a. In what ways, and to what extent, were those challenges addressed by your institution?
    b. In what ways, and to what extent, were those challenges addressed by outside organizations or factors outside your institution?
2. What were the most significant challenges to providing telehealth services, after the beginning of the pandemic?
    a. Have these changed as the pandemic has gone on longer?
    b. In what ways, and to what extent, were those challenges addressed by your institution?
    c. In what ways, and to what extent, were those challenges addressed by outside organizations or factors outside your institution?

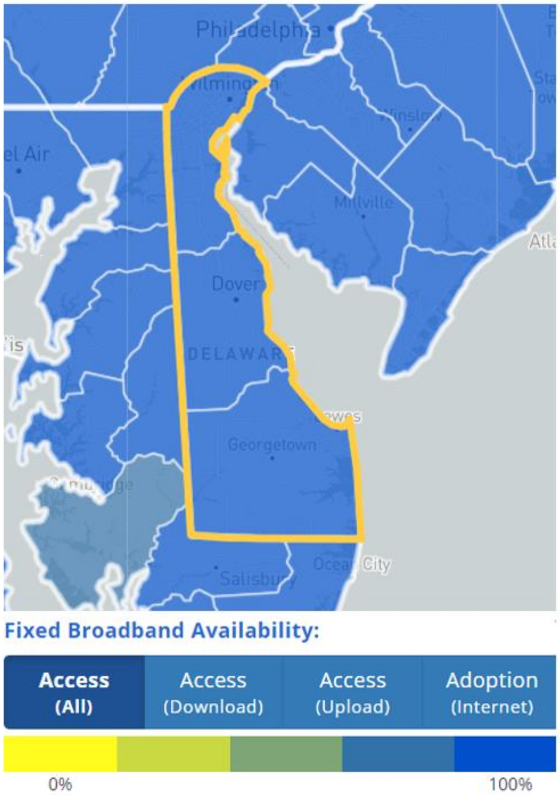
Appendix C.2.4 Questions about Remaining Needs

1. What challenges remain unaddressed?
2. Do you/your institution plan to continue offering services via telehealth following the pandemic?
    d. What changes do you foresee to how these services are offered?
    e. What problems would need to be addressed in order to continue offering these services?

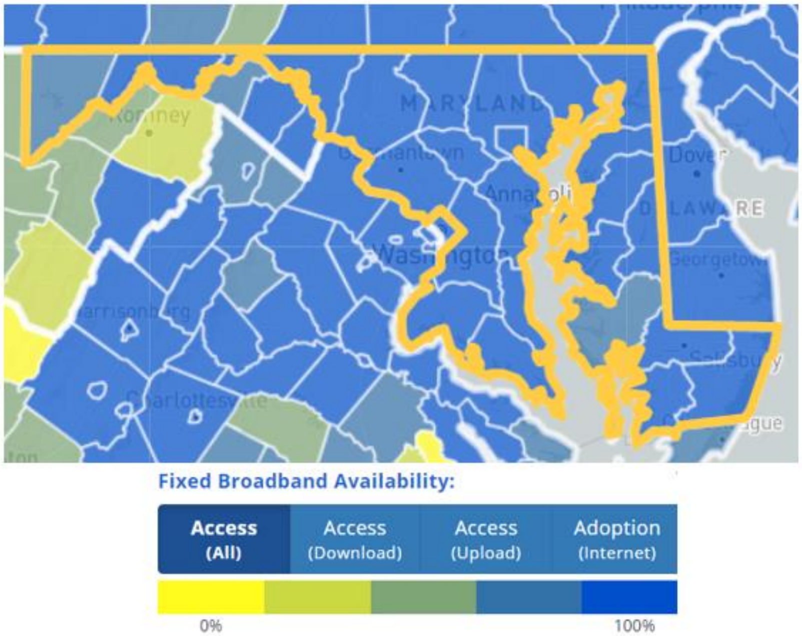
f. What outside assistance would you like to see from organizations like the regional genetics networks that may be helpful in continuing to offer telehealth services?
g. What policy changes would be helpful for yourself or for your institution in offering these services?

Appendix D Broadband Access Maps

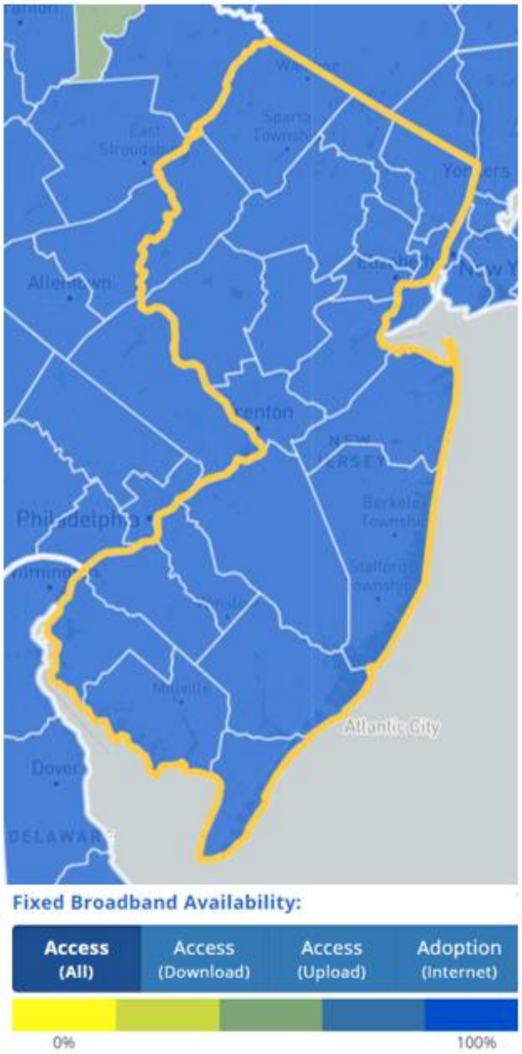
Appendix Figures 1-8, below, are maps retrieved from the Federal Communications Commission Connect2HealthFCC tool. The maps indicate the proportion of the population in each county with access to broadband service at a speed of 25/3 Mbps or higher for the states and territories of Delaware, Maryland, New Jersey, New York, Pennsylvania, Virginia, and West Virginia, as indicated (FCC, 2017). These maps were not available for Puerto Rico or the U.S. Virgin Islands. Instead, Figures 9 and 10 show the number of service providers providing broadband access at speeds of at least 25/3 Mbps within each county or census tract of Puerto Rico and the U.S. Virgin Islands. These maps in Figures 9 and 10 were retrieved from the Federal Communications Commission Fixed Broadband Deployment tool (FCC, 2020a).



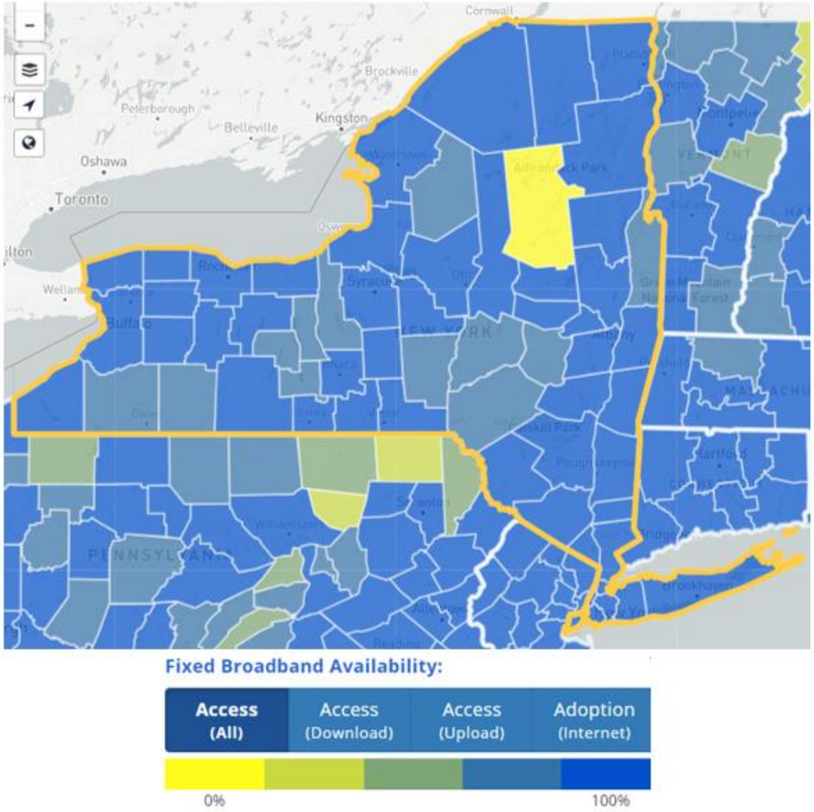
Appendix Figure 1. Delaware Broadband Access.



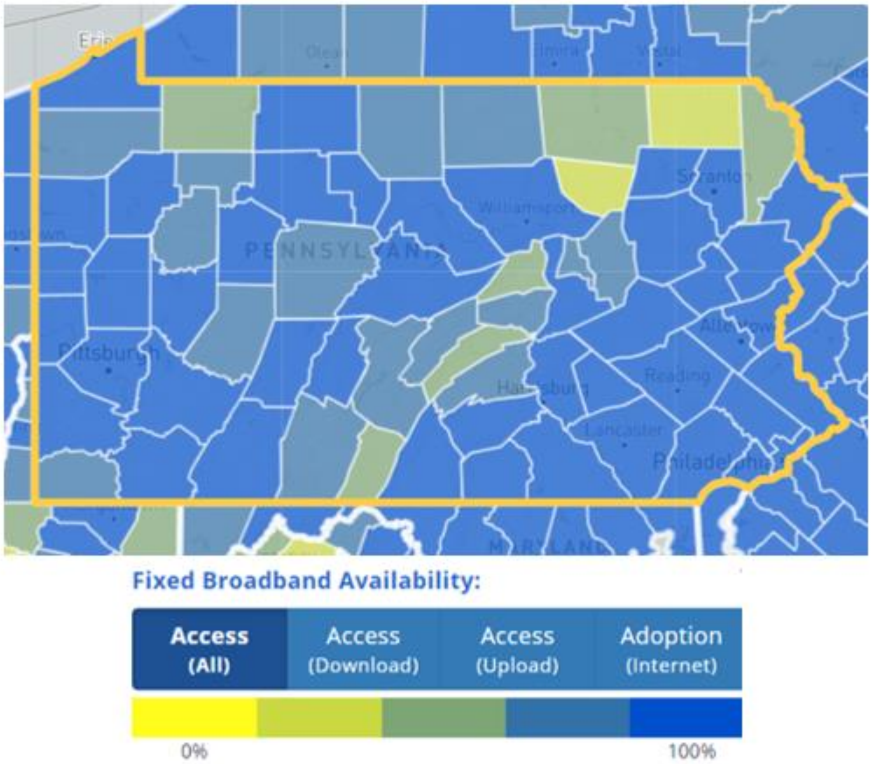
Appendix Figure 2. Maryland Broadband Access.



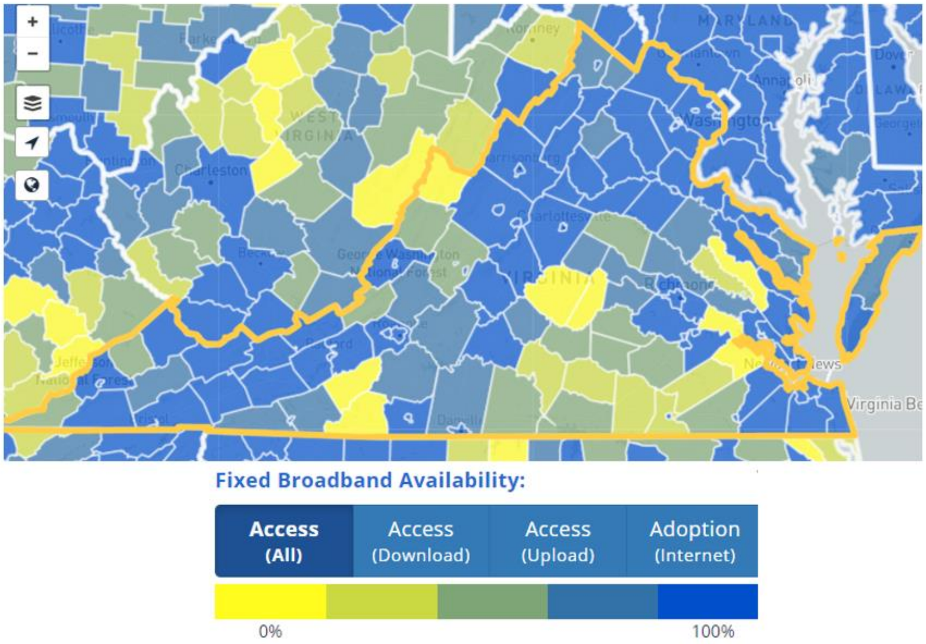
Appendix Figure 3. New Jersey Broadband Access.



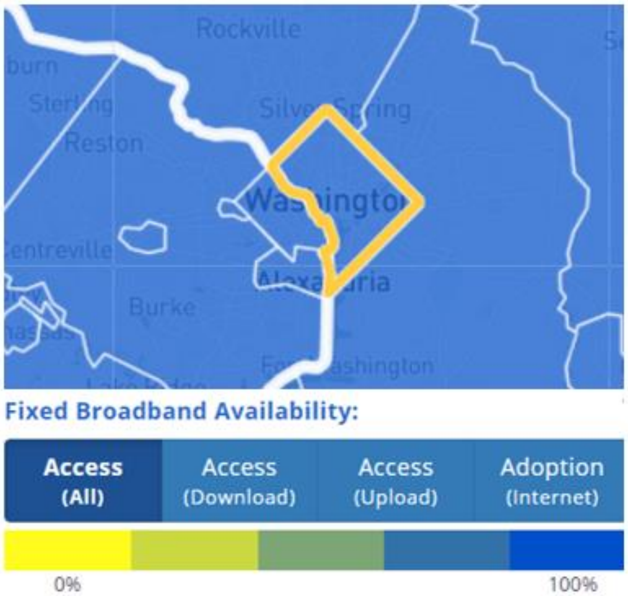
Appendix Figure 4. New York Broadband Access.



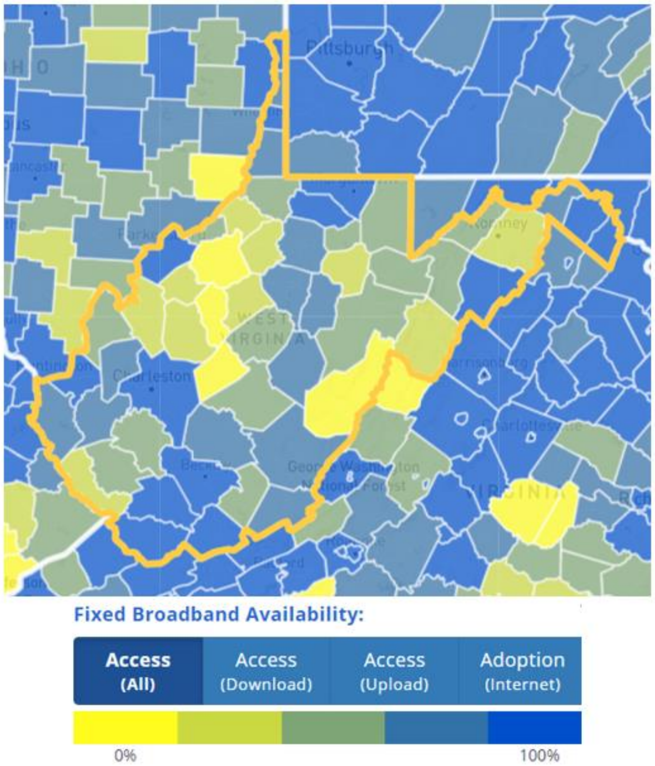
Appendix Figure 5. Pennsylvania Broadband Access.



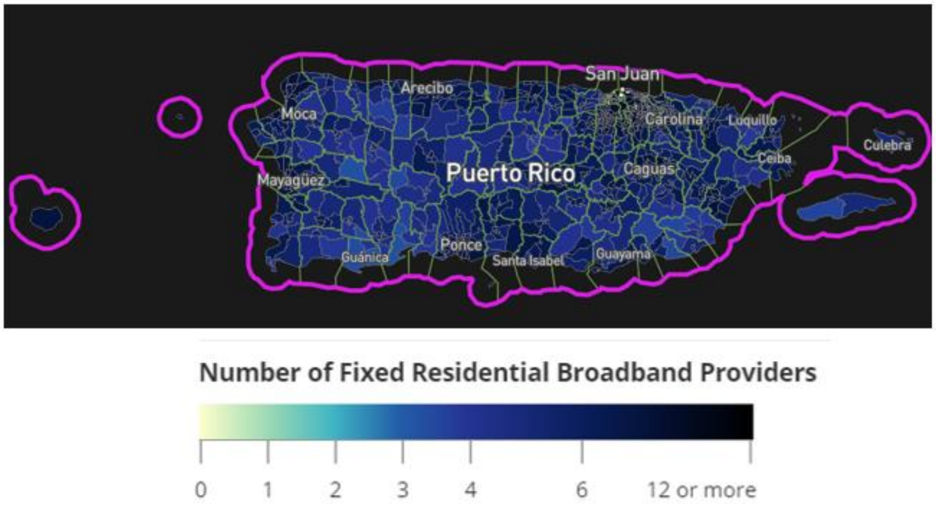
Appendix Figure 6. Virginia Broadband Access.



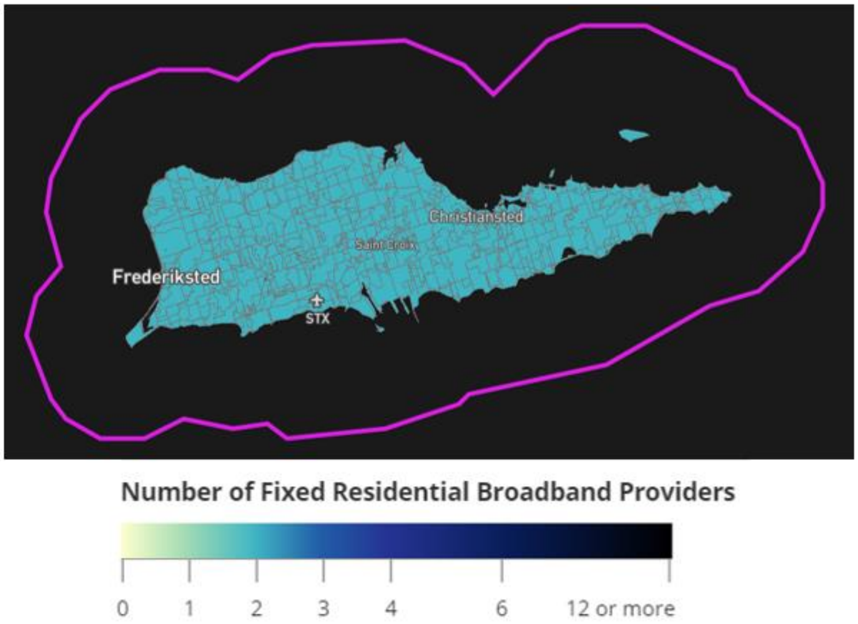
Appendix Figure 7. Washington, D.C. Broadband Access.



Appendix Figure 8. West Virginia Broadband Access.



Appendix Figure 9. Broadband Service Provider Availability in Puerto Rico.



Appendix Figure 10. Broadband Service Provider Availability in the U.S. Virgin Islands.

Bibliography

AAFP. (n.d.). What's the difference between telemedicine and telehealth? Retrieved from https://www.aafp.org/news/media-center/kits/telemedicine-and-telehealth.html#:~:text=Telehealth%20is%20different%20from%20telemedicine,to%20remote%20non%2Dclinical%20services.

ACMG. (2021). Find a Genetics Clinic. Retrieved from https://clinics.acmg.net/

AHA. (2020). *Hospitals and Health Systems Continue to Face Unprecedented Financial Challenges due to COVID-19*. Retrieved from https://www.aha.org/system/files/media/file/2020/06/aha-covid19-financial-impact-report.pdf

AJMC. (2020). A Timeline of COVID-19 Developments in 2020. Retrieved from https://www.ajmc.com/view/a-timeline-of-covid19-developments-in-2020

Aziz, A., Zork, N., Aubey, J. J., Baptiste, C. D., D'Alton, M. E., Emeruwa, U. N., . . . Friedman, A. M. (2020). Telehealth for High-Risk Pregnancies in the Setting of the COVID-19 Pandemic. *Am J Perinatol, 37*(8), 800-808. doi:10.1055/s-0040-1712121

Baker, J., & Stanley, A. (2018). Telemedicine Technology: a Review of Services, Equipment, and Other Aspects. *Curr Allergy Asthma Rep, 18*(11), 60. doi:10.1007/s11882-018-0814-6

Bauerly, B. C., McCord, R. F., Hulkower, R., & Pepin, D. (2019). Broadband Access as a Public Health Issue: The Role of Law in Expanding Broadband Access and Connecting Underserved Communities for Better Health Outcomes. *J Law Med Ethics, 47*(2_suppl), 39-42. doi:10.1177/1073110519857314

Bergstrom, K. L., Brander, T. E., Breen, K. E., & Naik, H. (2021). Experiences from the epicenter: Professional impact of the COVID-19 pandemic on genetic counselors in New York. *Am J Med Genet C Semin Med Genet, 187*(1), 28-36. doi:10.1002/ajmg.c.31855

Boothe, E., Greenberg, S., Delaney, C. L., & Cohen, S. A. (2021). Genetic counseling service delivery models: A study of genetic counselors' interests, needs, and barriers to implementation. *J Genet Couns, 30*(1), 283-292. doi:10.1002/jgc4.1319

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa

Buchanan, A. H., Datta, S. K., Skinner, C. S., Hollowell, G. P., Beresford, H. F., Freeland, T., . . . Adams, M. B. (2015). Randomized Trial of Telegenetics vs. In-Person Cancer Genetic Counseling: Cost, Patient Satisfaction and Attendance. *J Genet Couns, 24*(6), 961-970. doi:10.1007/s10897-015-9836-6

CDC. (2020). The 10 Essential Public Health Services. Retrieved from https://phnci.org/uploads/resource-files/EPHS-English.pdf

Cohen, S. A., Huziak, R. C., Gustafson, S., & Grubs, R. E. (2016). Analysis of Advantages, Limitations, and Barriers of Genetic Counseling Service Delivery Models. *J Genet Couns, 25*(5), 1010-1018. doi:10.1007/s10897-016-9932-2

Cooksey, J. A., Forte, G., Benkendorf, J., & Blitzer, M. G. (2005). The state of the medical geneticist workforce: findings of the 2003 survey of American Board of Medical

Genetics certified geneticists. *Genet Med, 7*(6), 439-443. doi:10.1097/01.gim.0000172416.35285.9f

Cosgrove, J., Achman, L., Holihan, M., Nurhussein, A., Suding, M., Friday, K., . . . Whitworth, J. (2020). *GENETIC SERVICES: Information on Genetic Counselor and Medical Geneticist Workforces*. https://www.gao.gov/assets/710/708545.pdf

DeGuzman, P. B., Bernacchi, V., Cupp, C. A., Dunn, B., Ghamandi, B. J. F., Hinton, I. D., . . . Sheffield, C. (2020). Beyond broadband: digital inclusion as a driver of inequities in access to rural cancer care. *J Cancer Surviv, 14*(5), 643-652. doi:10.1007/s11764-020-00874-y

Doyle, N., Cirino, A., Trivedi, A., & Flynn, M. (2015). Exploring barriers to payer utilization of genetic counselors. *J Genet Couns, 24*(1), 122-133. doi:10.1007/s10897-014-9745-0

Esakandari, H., Nabi-Afjadi, M., Fakkari-Afjadi, J., Farahmandian, N., Miresmaeili, S. M., & Bahreini, E. (2020). A comprehensive review of COVID-19 characteristics. *Biol Proced Online, 22*, 19. doi:10.1186/s12575-020-00128-2

FACT SHEET: The American Jobs Plan. (2021). Retrieved from https://www.whitehouse.gov/briefing-room/statements-releases/2021/03/31/fact-sheet-the-american-jobs-plan/

FCC. (2017). Connect2HealthFCC - Mapping Broadband Health in America 2017. Retrieved from https://www.fcc.gov/reports-research/maps/connect2health/index.html#ll=40,-95&z=4&t=insights&inb=in_bb_access&inh=in_diabetes_rate&dmf=none&inc=none&slb=90,100&slh=10,22

FCC. (2020a). Fixed Broadband Deployment. Retrieved from https://broadbandmap.fcc.gov/#/

FCC. (2020b). Household Broadband Guide. Retrieved from https://www.fcc.gov/consumers/guides/household-broadband-guide

FCC. (2021). *Fourteenth Broadband Deployment Report*. (14). Retrieved from https://docs.fcc.gov/public/attachments/FCC-21-18A1.pdf

Gausvik, C., & Jabbarpour, Y. (2021). COVID-19 Timeline: Centers for Medicare and Medicaid Services (CMS) Changes and Primary Care Support Were Not Enough to Prevent Practice Losses. *J Am Board Fam Med, 34*(Suppl), S7-s9. doi:10.3122/jabfm.2021.S1.200305

Guest, G., Bunce, A., & Johnson, L. (2016). How Many Interviews Are Enough? *Field Methods, 18*(1), 59-82. doi:10.1177/1525822x05279903

Hartnett, K. P., Kite-Powell, A., DeVies, J., Coletta, M. A., Boehmer, T. K., Adjemian, J., & Gundlapalli, A. V. (2020). Impact of the COVID-19 Pandemic on Emergency Department Visits - United States, January 1, 2019-May 30, 2020. *MMWR Morb Mortal Wkly Rep, 69*(23), 699-704. doi:10.15585/mmwr.mm6923e1

Hilgart, J. S., Hayward, J. A., Coles, B., & Iredale, R. (2012). Telegenetics: a systematic review of telemedicine in genetics services. *Genet Med, 14*(9), 765-776. doi:10.1038/gim.2012.40

HIMMS. (2021). *How the Pandemic Is Driving Healthcare Organizations' Investment in Technology*. Retrieved from https://www.cisco.com/c/dam/en_us/solutions/industries/healthcare/himss-pandemic-healthcare-investment-technology.pdf?oid=otrco024572&ccid=cc001799

Hirko, K. A., Kerver, J. M., Ford, S., Szafranski, C., Beckett, J., Kitchen, C., & Wendling, A. L. (2020). Telehealth in response to the COVID-19 pandemic: Implications for rural health disparities. *J Am Med Inform Assoc, 27*(11), 1816-1818. doi:10.1093/jamia/ocaa156

Hong, Y. R., Lawrence, J., Williams, D., Jr., & Mainous, I. A. (2020). Population-Level Interest and Telehealth Capacity of US Hospitals in Response to COVID-19: Cross-Sectional Analysis of Google Search and National Hospital Survey Data. *JMIR Public Health Surveill, 6*(2), e18961. doi:10.2196/18961

Hoskovec, J. M., Bennett, R. L., Carey, M. E., DaVanzo, J. E., Dougherty, M., Hahn, S. E., . . . Wicklund, C. A. (2018). Projecting the Supply and Demand for Certified Genetic Counselors: a Workforce Study. *J Genet Couns, 27*(1), 16-20. doi:10.1007/s10897-017-0158-8

HRSA. (2020). Telehealth Programs. Retrieved from https://www.hrsa.gov/rural-health/telehealth#:~:text=Telehealth%20is%20defined%20as%20the,public%20health%2C%20and%20health%20administration.

HRSA. (2021). What is Shortage Designation? Retrieved from https://bhw.hrsa.gov/workforce-shortage-areas/shortage-designation

HRSA. (n.d.). MUA Find. Retrieved from https://data.hrsa.gov/tools/shortage-area/mua-find

Khan, A., Cohen, S., Weir, C., & Greenberg, S. (2021). Implementing innovative service delivery models in genetic counseling: a qualitative analysis of facilitators and barriers. *J Genet Couns, 30*(1), 319-328. doi:10.1002/jgc4.1325

Maiese, D. R., Keehn, A., Lyon, M., Flannery, D., & Watson, M. (2019). Current conditions in medical genetics practice. *Genet Med, 21*(8), 1874-1877. doi:10.1038/s41436-018-0417-6

McDonald, E., Lamb, A., Grillo, B., Lucas, L., & Miesfeldt, S. (2014). Acceptability of telemedicine and other cancer genetic counseling models of service delivery in geographically remote settings. *Journal of Genetic Counseling, 23*(2), 221-228. doi:10.1007/s10897-013-9652-9

NCC. (2020a). Mission. Retrieved from https://nccrcg.org/mission/

NCC. (2020b). Providers Trained in Telehealth for Genetic Services. Retrieved from https://nccrcg.org/evaluation/#1531422402462-429a25af-570e

NSGC. (2021). Enhancing Medicare Beneficiary Access to Genetic Counselor Services. Retrieved from https://www.nsgc.org/Portals/0/Access%20to%20Genetic%20Counselor%20Services%20Act%20Issue%20Brief.pdf

NYMAC. (n.d.-a). Goals. Retrieved from https://www.wadsworth.org/programs/newborn/nymac/goals

NYMAC. (n.d.-b). NYMAC Project Summary Flyer. Retrieved from https://nymacgenetics.org/wp-content/uploads/2021/01/NYMAC-Project-Summary-Flyer.pdf

NYMAC. (n.d.-c). Telegenetics. Retrieved from https://www.wadsworth.org/programs/newborn/nymac/professionals/telegenetics

PCC. (2020). *Primary Care & COVID-19: Week 3 Survey*. Retrieved from https://www.pcpcc.org/2020/04/01/primary-care-covid-19-week-3-survey

Pereira, E. M., Ahimaz, P., Andrews, C., Anyane-Yeboa, K., Arsov, T., Berger, S. M., . . . Columbia University Clinical Genetics, P. (2020). COVID-19's Impact on Genetics at One Medical Center in New York. *Genetics in Medicine*. doi:10.1038/s41436-020-0857-7

Puro, N. A., & Feyereisen, S. (2020). Telehealth Availability in US Hospitals in the Face of the COVID-19 Pandemic. *J Rural Health*. doi:10.1111/jrh.12482

Rhoads, S., & Rakes, A. L. (2020). Telehealth technology: Reducing barriers for rural residents seeking genetic counseling. *J Am Assoc Nurse Pract, 32*(3), 190-192. doi:10.1097/jxx.0000000000000373

Shah, N. N., Fleisher, L. D., Andersson, H. H., Butler, B. B., Thompson, B. H., Benkendorf, J., . . . Watson, M. S. (2009). *Impediments and Solutions to Telegenetics Practice: Meeting Report*. Retrieved from https://nccrcg.org/wp-content/uploads/2018/10/ACMGTelegeneticsPolicyMeetingReportFINAL.pdf

Shur, N., Atabaki, S. M., Kisling, M. S., Tabarani, A., Williams, C., Fraser, J. L., . . . Summar, M. (2021). Rapid deployment of a telemedicine care model for genetics and metabolism during COVID-19. *Am J Med Genet A*, *185*(1), 68-72. doi:10.1002/ajmg.a.61911

Solomons, N. M., Lamb, A. E., Lucas, F. L., McDonald, E. F., & Miesfeldt, S. (2018). Examination of the Patient-Focused Impact of Cancer Telegenetics Among a Rural Population: Comparison with Traditional In-Person Services. *Telemed J E Health, 24*(2), 130-138. doi:10.1089/tmj.2017.0073

Terry, A. B. (June 4, 2021). [Personal communication].

Terry, A. B. (May 25, 2021). [Personal communication].

Terry, A. B., Wylie, A., Raspa, M., Vogel, B., Sanghavi, K., Djurdjinovic, L., . . . Bodurtha, J. (2019). Clinical models of telehealth in genetics: A regional telegenetics landscape. *J Genet Couns, 28*(3), 673-691. doi:10.1002/jgc4.1088

U.S. Census Bureau. (2010). *U.S. Virgin Islands Summary File*.

U.S. Census Bureau Population Estimates Program. (2019). QuickFacts. Retrieved from https://www.census.gov/quickfacts/fact/table/US/PST045219

Voils, C. I., Venne, V. L., Weidenbacher, H., Sperber, N., & Datta, S. (2018). Comparison of Telephone and Televideo Modes for Delivery of Genetic Counseling: a Randomized Trial. *J Genet Couns*, *27*(2), 339-348. doi:10.1007/s10897-017-0189-1

Vrecar, I., Hristovski, D., & Peterlin, B. (2017). Telegenetics: an Update on Availability and Use of Telemedicine in Clinical Genetics Service. *J Med Syst, 41*(2), 21. doi:10.1007/s10916-016-0666-3

Woodall, T., Ramage, M., LaBruyere, J. T., McLean, W., & Tak, C. R. (2021). Telemedicine Services During COVID-19: Considerations for Medically Underserved Populations. *J Rural Health, 37*(1), 231-234. doi:10.1111/jrh.12466

WSRGN. (2017). Telegenetics Training Project. Retrieved from https://www.westernstatesgenetics.org/project-activities/telegenetics-training/

Zierhut, H. A., MacFarlane, I. M., Ahmed, Z., & Davies, J. (2018). Genetic Counselors' Experiences and Interest in Telegenetics and Remote Counseling. *J Genet Couns, 27*(2), 329-338. doi:10.1007/s10897-017-0200-x