

An Exploratory Investigation of Genetics Health Services in Virginia

by

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B.S., Virginia Polytechnic Institute and State University, 2019

Submitted to the Graduate Faculty of the

Department of Human Genetics

Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Public Health

University of Pittsburgh

2021

UNIVERSITY OF PITTSBURGH
GRADUATE SCHOOL OF PUBLIC HEALTH

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April 30, 2021

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Abstract

Health care efficacy ranges over multiple influential components, not confined only to personal details such as demographics, but also more external variables such as socioeconomic status or area of residence. The impact also influences specified health care services like genetics, creating concern for public health due to the varied impact residents experience because of factors out of their control. This investigation assesses the current state of both general health care services and genetics services for residents within Virginia, a state that contains numerous subpopulations of interest. This study utilized census data and data from the County Health Rankings & Roadmaps to assess the split of urban and rural counties, which have incredibly different needs due to these variables. Analysis of information like area of residence, mean household income, and proportion of residents uninsured can inform providers where mitigation efforts could be best tailored towards. This is only amplified when specified health care recipients can be surveyed about their experiences and perceptions of care, permitting individual-level feedback as was done within this study. County-level data showed that urban residents tend to have higher mean household income and have a higher probability of being insured than their rural counterparts. A survey of Virginia residents regarding genetic services was also developed and distributed. Respondents stated lack of educational resources, long wait times for preliminary appointments, and dissatisfaction with mental/emotional support, showing there are numerous avenues for improvement. Though these trends reflect a bleak status of health services, opportunities within telehealth and family-to-family

support networks provide exciting chances to enact change. However, this must be paired with cohesive and coherent effort from health care providers to minimize barriers and help those currently disadvantaged.

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1.0 Introduction

The existence of genetics healthcare services provides strong opportunity for life-long benefits to recipients. As a specialized form of health care, it presents the opportunity to change or affect outcomes of disease that have a genetic basis and typically have no direct cure. Its study and execution are becoming more prevalent within existing infrastructure of health care provision in the United States, creating interaction and implementation of these services more regularly. It is naïve to argue that genetics health care services, such as genetic testing, diagnostics, and genetic counseling can be effectively parsed from the standard model of health care. Therefore, to understand the interactions between standard health care provision and genetic health care services, they must be considered as a cohesive unit before being more uniquely observed. This grows in complexity as issues present within general health care services may be equally embedded into the provision of genetic health care services. It is also inevitable that given genetics health care services are a subset of general services that patients may face new and unique challenges within this field. Regardless, it is of vital necessity to ascertain where genetic services lag further behind general health care, particularly within a geographic area.

1.1 Existence of Disparity in Health Care

It is a fairly evident fact of publications throughout the past few decades that the existing system of health care in the United States is perceived as unfair, however that some issues persist

within patient perception including poor communication, cultural competence, and general physician-patient encounters being rated unfavorably (Johnson et al., 2004; Jha et al., 2008). Multiple approaches have been taken to elicit the trends in where the disparities exist, and there have been multiple stratified groups determined to be under-served. Studies have focused on challenges faced by rural residents in comparison to urban residents, with findings illustrating that residence dictates the access to care, as well as the offerings in terms of specialized health care (Van Dis, J., 2002; Johnson et al., 2006). One publication reported a decrease in health care outcomes related to levels of screening and access to providers for rural residents in comparison to urban residents, with mixed results across racial/ethnic groups such as non-Hispanic whites, African Americans, and Hispanic populations (Caldwell et al., 2016). Though there were mixed results, the researchers argued that some of the trends were co-linear with other variables such as socioeconomic status.

Breaking these trends of co-linearity is a large hurdle to overcome within public health. Poverty itself creates a significant risk for poor health and poor health outcomes. When comparing residents of rural and urban areas, a higher proportion of rural residents lived in poverty, yet both rural and urban groups experienced gaps in health care access (Blumenthal, S., 2002). This is not an illustrative comparison, however, as each grouping faces unique challenges. Urban residents are more likely to be met with overcrowded housing and mental illness, while rural residents are more likely to encounter health care delivery models that categorize all rural populations as homogenous along with issues of being in proximity of a provider. A 2002 article argued that this “one-size-fits-all” approach exacerbated issues, only creating further inequities within an unstable delivery mechanism (Heady, H., 2002). One example of this is in relation to Congressional policymaking, where policymakers focus much more frequently upon more urban populations

since 80% of residents reside within “non-rural” areas (Heady, H., 2002). The policy in effect at time of publication for Medicare hospital reimbursement had a payment rate variable upon area wage index; however, there was only one index for the entirety of the state (Heady, H., 2002). States that are non-homogenous in their rural population are heavily affected by these laws. Each approach to a rural area must not only take the factor of being classified as rural into account, but also the demographic makeup, the agents acting as delivery mechanisms, the socioeconomic status of the region, and extraneous variables such as travel time to health care provider.

One of the most well-documented disparities within health care provision is by racial and ethnic groups. The Center for Disease Control and Prevention’s report on racial and ethnic health disparities between 2012 and 2015 provides one of the most cohesive insights to this issue. Totalling 263,054 respondents, self-reported metrics pertaining to health-related quality of life were significantly more likely to be fair or poor in a higher proportion of Black, Hispanic, Asian or Native Hawaiian or Pacific Islander (NHOPI), and American Indian/Alaska Natives (AI/AN) in comparison to non-Hispanic Whites (James et al., 2017). This disparity shows an increase in the health system to function for White residents before other racial/ethnic groups, and that the variable of racial/ethnic groups must be considered in comparisons between rural communities. When considering access to health care and use of health care metrics, adults in Black, Hispanic, and AI/AN racial/ethnic groups reported significantly higher proportions of times that they could not see a doctor in the past 12 months simply due to cost (James et al., 2017). Finally, chronic health conditions were more prevalent in non-Hispanic black, Hispanic, Asian/NHOPI, and AI/AN Americans than White Americans (James et al., 2017). The researchers implored for further research into why these trends exist and indicated that more focused efforts to provide culturally sensitive care may strengthen prevention efforts.

Translating health care to a particular group or community is a time-consuming challenge, yet can provide for improvement that is beneficial for that community. Enacting this approach in underserved areas can provide a feedback loop between patients and providers, constructing a more tailored approach. Engaging stakeholders and community members in focus groups can allow for modification within the system where a gap may exist, potentially removing it and fixing the overall impediment. Public health is comprised of ten essential services, one of them being to mobilize community partnerships, which continues to drive development of effectively catered programs. Many instances of this exist, such as one study where researchers pursued this community-targeted approach by directly engaging members of the community and asking about their perceptions. Implementation was within rural Appalachian communities, providing data on what the community identified to be existing barriers, particularly the cultural expectations of healthcare for Appalachian residents, perceived barriers, and coping strategies, all of which prevent healthcare use to its full potential (Pieh-Holder et al., 2012). This study effectively interacted with the community by using six total focus groups in multiple locations rated to be highly familiar with participants. The findings of this study further informed healthcare providers what perceptions existed, allowing for those stakeholders to change simple variables such as hours and culturally-relevant programs to effectively reach the population they were serving (Pieh-Holder et al., 2012). Simply through listening to the community, qualitative data can guide health care providers in minimizing the existing gaps.

1.2 Genetics Health Care Services

Understanding the gaps within general health care services provides insight as to what gaps are liable to persist within genetics services, but it also is not entirely encapsulated within the same confines. Genetics health care services face a litany of further challenges that are not unique in their nature yet are not present as consistently within other services. The first and arguably most impactful is the complexity of genetics.

Health literacy is defined as “the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions,” also encompassing access to health information and effective use of that information, per the World Health Organization (WHO, 2019, p. 20). Health literacy itself is already an issue as researchers have found persisting themes of lower health literacy correlating to increased incidence of non-communicable diseases, particularly in that individuals may understand tenants of health, but they are unable to effectively translate that knowledge to implementation (Liu et al., 2020). Other studies have found that health literacy significantly differs between groups based on multiple variables, such as income, education, race/ethnicity, and age (Zahnd et al., 2009). When controlling for each of those variables, however, there is a significant difference between rural and urban residents (Zahnd et al., 2009), exhibiting how variable health literacy can be not just within a community, but also between communities.

Genetic literacy itself, however, presents a new level of the issue. Even when educational modules were provided to college-educated participants, assessment scores relating to basic genetic concepts still fell between 40% and 55% (Pearson & Liu-Thompkins, 2012). Studies have shown that the increasing use of genetic testing has resulted in health care professionals needing to effectively communicate findings to families (Lea et al., 2011). Although this can be done,

ensuring that the approach is amenable to varying levels of general health literacy, the approach must be improved. Researchers have devised methods to evaluate genetic literacy including the Rapid Estimate of Adult Literacy in Genetics, or REAL-G as a tool. Modeled after an already existing general health literacy model, this metric provided significant correlation as a predictive model of genetic health literacy and could be used as a tool for clinicians to ensure the best language for communication with patients (Erby et al., 2008). The caveat to an approach such as this is just like in studies evaluating knowledge of concepts, it still does not effectively evaluate the deep understanding required. These approaches highlight the innate complexity of genetics that must be considered.

The current state of medical genetics also gives reason for concern and hope for improvement. There is an anticipated increase in employment of genetic counselors of approximately 21% throughout the next decade (U.S. Bureau of Labor Statistics, accessed Sept. 2020), but that simply may not be a rapid enough increase. Furthermore, this is simply regarding the outlook for job openings and not the number of counselors actually practicing. A 2019 report outlined that although the quantity of practicing professionals (including medical geneticists, genetic counselors, and other genetics professionals) had significantly increased, there were a majority of professionals who reported that they could not see new patients within a month's time (Maiese et al., 2019). The same report stated that nearly half of organizations polled had geneticist job vacancies, and that the existing system must undergo significant changes to ameliorate these issues (Maiese et al., 2019).

Within medical geneticists and genetic counselors, the two primary groups of genetics professionals, there is room for improvement regarding patient-based perceptions. One study followed 130 women affected by genetic conditions in Kentucky, with four being focused upon in

case studies. These cases were identified by rural outreach programs that aimed to address barriers such as social and geographical disadvantages, providing genetic services such as genetic diagnosis and counseling (Kelly, S., 2002). Some issues outlined were primarily based in insurance coverage and costs, with some instances involving parents choosing between health care for a child affected by genetic conditions or their own health conditions that are causing their health to deteriorate (Kelly, S., 2002). Families also reported other issues, including that physicians ignored their insistence for help, which delayed referral to genetic evaluation and testing (Kelly, S., 2002).

More recent research has begun to explore the perception of genetics and genetics health care services within rural populations. Research has continually been done focusing on at-risk individuals or families, ignoring the general public's general perception. A survey was constructed to evaluate rural Midwestern United States residents and their attitude towards genetic counseling, as well as providing both accurate and inaccurate information to assess perception of what genetic counselors did. The survey found that despite a void of specific education and familiarity with genetic counseling, respondents had accurate perceptions of genetic counseling, even pertaining to who may benefit from genetic counseling. There were also written statements from many survey respondents outlining their answers, with some stating a prevention-focused approach involving genetics was a part of their reasoning (Riesgraf et al., 2015). Overall, the study illustrated that rural residents perceive genetics professionals as helpful and beneficial to their health care.

In comparison, it is also vital to evaluate the perception of practicing genetic counselors on their ability to assist their patients. Though gaps exist, many are attempting to reach rural communities to provide the necessary appointments and counseling. The apparent demand for these rural-facing professionals seems to be less necessary than the necessity in larger urban communities, yet the more rural-tailored approaches seem to be rather successful. A 2018 report

showed that when evaluating on a 3-point Likert scale ranging from dissatisfied to very satisfied, genetic counselors practicing in areas classified as rural reported a significantly higher variety of patients and cases as well as overall satisfaction (Emmet et al., 2018). The rural classification was designated per the Rural-Urban Commuting Area Codes (RUCAs), a metric developed to evaluate distance to urban areas and integration with those urban areas, weighing variables such as population density and daily commuting time by residents (USDA ERS, accessed January 21, 2021). There were a few other notable findings, such as that salary and advancement opportunities were not rated lower than average responses throughout all respondents. The only notable yet insignificant difference between urban and rural genetic counselors was concerning delivery of service and education, where challenges arose and there was a slightly higher requirement of ingenuity to reach patients (Emmet et al., 2018). Regardless, this publication outlined that genetic counselors are satisfied in practicing in rural setting and that this can be an effective way to reach more geographically isolated populations.

Due to the genetics workforce shortage many have advocated for increased education in Primary Care Providers (PCPs) to serve as liaisons until genetics professionals can meet demand (Harding et al., 2019). As genetics has rapidly become more integrated into health care services, the coordination of multiple agents is necessary. Researchers found that PCPs reported a lack of knowledge as to when a referral to a geneticist was appropriate, advocating for further education (Harding et al., 2019). The aim is not to have PCPs serve as the primary source of information, but rather be a guiding tool while genetic health care providers continue to expand to novel areas and regions. Until then, alternative service delivery models are of the utmost importance.

1.3 Alternative Service Delivery Models

1.3.1 Telehealth and Telegenetics

Telehealth and teleconsultation have been present as health care delivery models through multiple avenues. It has previously been executed through phone consults, yet with continuing advancements in technology and availability of connection to the internet, video conferencing has helped spur it further. Studies have shown that general practitioners can benefit from the use of teleconsultation, as it was a method by which to save resources (Zanaboni et al., 2009). Though its usefulness is dependent upon the specialty, the study showed that it could effectively reach isolated patients in a timely manner, providing opportunity to seek further medical assistance if necessary.

Translating this to genetic services specifically, multiple benefits may be found. Researchers at Duke University explored cost difference, patient satisfaction, and patient attendance in telehealth compared to conventional in-person cancer genetic counseling appointments. There are significant upfront costs associated with telehealth in establishing a secure connection with appropriate software and adequate communication technology, so assessing the cost is a necessary variable. The study found that although the upfront cost existed, there was a total cost reduction of 57% for telegenetics patients in comparison to conventional patients, with no significant difference in patient satisfaction (Buchanan et al., 2015). This cost savings included the cost for a genetic counselor to train clinic personnel at the rural clinics. The only negative finding within this study was a difference in attendance between groups, with conventional appointments having an 89% attendance rate compared to 79% for telehealth (Buchanan et al.,

2015). These benefits outlined the potential of telehealth nearly a decade ago, but for some barriers to implementation remain difficult to overcome.

It is important to consider the factors that have continued to push telehealth, especially in recency. The COVID-19 pandemic has been one of the most significant agents of telehealth promotion as many health care providers had no other choice when lockdowns commenced. Studies reported that although telehealth was a portion of the existing health care infrastructure, an institution with “high telehealth” use reported approximately 100 telehealth consults per day, whereas the global pandemic caused many institutions to inflate to over 1000 telehealth consults per day (Wosik et al., 2020). Telehealth has been essential throughout the pandemic, and without it many patients would have been unable to get necessary treatment or consultation. However, its rapid adoption has not prevented issues from arising, particularly those associated with having the necessary infrastructure to execute telehealth. By taking this instance as a learning opportunity, it permits future development towards use of telehealth on a regular basis rather than in an emergency when no alternatives exist.

The desire to operate through telehealth has been shown throughout studies of genetic counselors. A 2018 study compared the perception of telehealth and telegenetics between genetic counselors who have and have not used them, with varying results based upon previous use (Zierhurt et al., 2018). The study found that the most appealing characteristic to those who have used it was the innovation of this alternate service delivery model, whereas the biggest potential pitfall was inability to gather all nonverbal communication from patients. Though these were the most widely held perceived benefits and detriments, the largest perceived barrier was stated to be billing and reimbursement (Zierhurt et al., 2018). Overall, genetic counselors who had previously used telehealth services stated satisfaction, and those who had not yet implemented it expressed

near-universal interest of using telehealth. If billing and reimbursement are the largest impediments from implementing telehealth, it is fair to argue that the global pandemic's presence may spur improvement on this front. However, the pandemic has created novel challenges in relation to state licensures. The Center for Medicare & Medicaid Services (CMS) provided an emergency declaration for health care providers at the beginning of the pandemic which provided blanket relief of state licensure requirements (CMS, 2020), effectively relaxing in-state licensure requirements for numerous health care providers. However, this did not include genetic counselors. This arose because genetic counselors are not recognized by CMS to operate independently when serving Medicare beneficiaries, preventing the use of the 1135 waivers referenced in the CMS emergency declaration (National Society of Genetic Counselors, 2020). There is opportunity for removal of this barrier with the proposed Access to Genetic Counselor Services Act of 2019, which would permit coverage through Medicare beneficiaries (Loebsack, D., 2019), but its referral to subcommittees has stymied the opportunity for rapid response within this pandemic.

Within the New York Mid-Atlantic Consortium (NYMAC) of the Regional Genetics Network, there have been investigations into the state of existing infrastructure and other potential pitfalls to the use of telegenetics throughout the region. One noted issue throughout the pandemic is the burden upon patients to have appropriate technology as well as the ability to maintain adequate internet access for consultations. The NYMAC study, completed prior to the pandemic, noted a split between use of phone-only and video-conferencing telehealth appointments, possibly leading to variable outcomes for patients. The study reported that continued investigation is necessary to gain insight as to where to improve each method of delivery, hopefully learning more about the differences between these methods (Terry et al., 2019). The researchers deemed their data inconclusive but determined that more formal evaluation must be done on the numerous

methods that can improve patient access. Regardless of this detail, the use of telehealth to reach patients is of increasing importance.

We cannot ignore, however, that practicing health care services in person has notable value. Outlined throughout aforementioned publications is the utility of in-person genetic counseling appointments, with in-person appointments more likely to be attended (Buchanan et al., 2015). These physical appointments are thought to possibly provide a better opportunity for direct communication between the patient and the provider, especially when patients may be uncomfortable using a computer, but this study did not find a significant difference between in-person and telehealth practices for self-reported satisfaction with appointment (Buchanan et al., 2015). There are also noted benefits concerning logistics with in-person genetic counseling appointments, such as billing or genetic testing. One study found that telehealth made coordination of blood draws or patient signatures more difficult, however the participants all argued that the benefits outweighed the barriers (Cohen et al., 2016). Susan Kelly outlined the difference in going to rural residents, stating that the location in which medical encounters occurred was vital (Kelly, S., 2003). Going to a community as a professional provides an incommunicable level of trust with the patient, as respondents in her study stated that traveling to urban health care centers seemed to yield a disconnect between them and their health care providers (Kelly, S., 2003). Thus, telehealth is not a perfect service delivery model in all instances. Instead, it can hopefully create a new avenue to reach patients.

1.3.2 Community-Based Networks

An effective bridge to ensuring localized and targeted service is through community-based practices. These methods are imperfect yet allow for a better integration between health care

providers and the community in which they are operating. Evidence has shown that education and health literacy serve as one component to improve self-care and self-management (Paasch-Orlow & Wolf, 2020). Instead of placing this burden of education on PCP's and other health care providers, it is possible for it to be offloaded to the community in the basis of a support network.

Community-based health care and networks are not a novel concept. Their use has been previously explored, with findings illustrating the utility of community-based organizations as an essential component to reduce disparities (Jenkins et al., 2010). This has been furthered by arguments that patients are more likely to cooperate and collaborate with community members than health care providers, as the social support provides somewhat of a safety-net for that patient (Peek et al., 2014). Other research has shown that these community-based efforts provide avenues to mitigate barriers, such as reduction of prices of produce to promote healthy dietary choices in diabetic populations where monetary resources may be limited (Peek et al., 2012). These methods may not work ubiquitously in every setting, but they at least provide the opportunity to tailor approaches toward the community.

Health care faces a significant challenge in terms of education, but there is evidence that community-based education methods are effective. A 1996 review of community-focused education discussed that education efforts must empower the patient, with educators being flexible enough to expand outside of their preconceived notion of the community to provide the most expansive amount of education possible (Habbick & Leeder, 1996). These community education efforts are also helpful because they do not only empower the patient but have also been found to increase self-driven motivation to implement community-focused education within health care providers (Okayama & Kaji, 2011). However, scenarios will arise in which involvement of a health

care provider is not immediately available, so a level of understanding and knowledge within the community members themselves is a key consideration.

Family-to-Family networks provide this opportunity of community-based knowledge, with members being able to refer to one another for information and support. This method of education and sharing of information has not been studied extensively, but some qualitative data has been aggregated from specific populations. Particularly within communities of parents of children with special needs, these parent-to-parent or family-to-family networks have the opportunity for education, but also mutual emotional support (Ainbinder et al., 1998). Participants within these networks outlined that it was helpful to receive support through a “reliable ally” that had a perceived similarity of challenges they were facing, commonly referred to within this community as “perceived sameness” (Ainbinder et al., 1998). Another research study did a qualitative analysis of these family-to-family networks and found similar results, with some of the most prominent being that the families were able to cope better with their situations after hearing of others’ similar challenges, as well as that this methodology provided significant benefit for families even in lower socioeconomic brackets (Singer et al., 1999).

The emergence of internet-based family-to-family networks has also changed what opportunities exist. Anecdotally, families have discussed how discovery of these networks is no longer a happenstance process but is now an entity that can be sought out for connection between families even with rare conditions (Mathiesen et al., 2012). Some reviews of this method argue that it is an effective supplement to provider-based education, removing any barriers of distance, and being an around-the-clock mental well-being support network (Niela-Vilen, 2014). The further development of these communities over the internet provides opportunity for educational materials to be saved as a repository as well, allowing for new members of the community to have a

consolidated list of materials to refer to. Altogether, the evidence supports that whether they are in-person or virtual, these family-to-family/parent-to-parent networks provide strong opportunities for education and support.

1.4 The Commonwealth of Virginia

The Commonwealth of Virginia is intriguing when considering the multiple variables at play related to genetics services. Embedded within the New York Mid-Atlantic Coalition for Regional Genetics (NYMAC), it provides a unique landscape that is comparable to other states in some ways, such as geography and proximity to super-metro areas, while also having unique subpopulations. The goal is not to provide an omniscient perspective about the variables at play, but instead consider some of the more influential ones.

One of the most evident factors when considering Virginia is the major cities involved. Within its borders is the capital of Richmond, home to multiple health care institutions and a university medical center, Virginia Commonwealth University. This university is particularly notable as it is the only educational institution within the state that is accredited to have a genetic counseling program. Although other universities have strong ties to research in genetics and public health, this is the only one training genetic counselors that will eventually enter the field. The next clustering of cities that are within Virginia are surrounding the nation's capital, Washington, DC. Cities and counties such as Fairfax, Alexandria, Arlington, Prince William County, and Loudon County have many professionals tied to genetic health care services. Given the proximity to the National Institutes of Health's headquarters in Maryland, this region has many well-renowned hospitals and research organizations. The final major region within Virginia is Hampton Roads,

home of Eastern Virginia Medical School (EVMS) and the Sentara Healthcare headquarters. Also, within Norfolk, Virginia is the Children's Hospital for the King's Daughters (CHKD), the only independent Level I Pediatric Trauma Center in the state. As an affiliate to the EVMS system, CHKD provides numerous genetics health care services and employs numerous genetics professionals.

Exterior to the major urban areas, there are smaller communities where significant research is being done. Roanoke, Virginia, although a city itself, is expanding its reach through research in coordination with Virginia Tech. Charlottesville is home to the University of Virginia Health System, which works in coordination with a number of local companies and organizations that are classified as the Charlottesville Biohub. Other regions of Virginia do have connection to alternate health systems and research companies, but the largest agents within health care and genetics are housed within these cities and areas.

Another largely influential factor that makes Virginia an intriguing state to study is the topography of the state. Regions of the state vary wildly, with geological features such as the Eastern Shore and the Appalachian Mountains creating isolated communities. Studies have shown that residents in regions, particularly in Appalachia, have reduced access to health care such as dental and vision care (Huttlinger et al., 2004). Appalachia also presents a unique environment given the regional identity for many individuals. This identity ties back to the preconceived notions many rural residents face when dealing with medical professionals, similar to the previously mentioned residents in Kentucky (Kelly, S., 2002). In contrast, the Eastern Shore is barred by more substantial physical barriers in terms of access to care. The Eastern Shore is only connected to the rest of Virginia by the Chesapeake-Bay Bridge-Tunnel, which spans the mouth of the Chesapeake

Bay. Otherwise, the only ways to access the mainland of Virginia is by either routing through Maryland or crossing the Chesapeake Bay by ferry.

Some other factors that may be worthwhile when considering the state are political and social factors. Virginia has historically been a swing state in election years, is home to the largest military area in the world in Hampton roads, and is at a delicate balance in distance between other major cities. Anecdotally, it is not uncommon to hear about an individual needing specialized health care and leaving the state to go to Baltimore, MD or Durham, NC for a specialist. This can be an issue when agents such as health care providers want to ensure their patients are having their needs met. In many instances, the time investment of traveling two hours to Richmond or two and a half to Durham for a more highly trained doctor is seen as a worthwhile tradeoff. Virginia faces this challenge uniquely in comparison to its neighboring states, with its closest relative potentially being Pennsylvania. However, it could be argued that Pennsylvania is still differentiated as it has two metropolitan areas that serve as flagship locations for health care with a third in the central region of the state, being Geisinger Medical Center in Danville. Regardless of that, Virginia is in a precarious state and health care providers must determine how they will reach their patients in an effective manner. Community-based efforts do exist to mitigate these, such as Virginia Commonwealth University's Center for Family Involvement and family-to-family network. As it is not solely restricted to Richmond and operates heavily online, it provides an outlet for support and communication between families affected as well as education. Even with these efforts, coordination between these entities, their similar communities, and the practicing professionals is of great importance.

2.0 Specific Aims

This assessment aims to evaluate several issues in health care as well as specializations within genetics. This will consist of a two-pronged approach to evaluate two sections of health care in Virginia. These will be the overarching trends of general health care provision and the unique trends experienced within genetic services.

- Assess the existing health care landscape in Virginia by evaluating different classifications of rural and urban centers and county-based metrics to label differences in jurisdictions.
- Assess information regarding population size and mean household income to understand the impact those play into population-level differences in Virginia to further clarify the disparities existing on a county-level and whether a rural and urban classification is of significance.
- Assess whether those same variables are fully explanatory or whether there are further lurking variables affecting the differences between rural and urban classifications.
- Develop a survey targeted towards parents and families who have received genetics services within the state of Virginia and are residents of Virginia, primarily consisting of a Likert-scale grading of responses and expansion of responses when desired. This survey will cover:
 - The class of genetic services
 - Basic residence information such as zip code
 - Time until first appointment

- Qualitative questions regarding opinion of services offered and how effective they were at accessibility, education, and outreach.
- Self-perception questions regarding health literacy.

3.0 Methods

A mixed approach was decided upon for this study due to the two separate arms of investigation. The first arm is the secondary data analysis of county health factors and health outcomes, and the second arm being the primary data obtained through the survey. The survey was approved through the University of Pittsburgh's Institutional Review Board, and the approval is provided in the Appendix (Appendix A).

3.1 Secondary Health Factors and Outcomes Data

Most analysis was performed on county-level health factors and health outcomes data aggregated from various surveys and presented by the University of Wisconsin Public Health Institute in the County Health Rankings (PHI, University of Wisconsin, n.d.). The county health factors are comprised of a number of components and are divided into four major categories: Physical Environment, Social and Economic Factors, Clinical Care, and Health Behaviors. These variables are weighted at different levels and account for the entirety of health factors rankings and scores. As for the health outcomes, that data is equitably split between length of life and quality of life metrics.

These health factors and health outcomes encapsulate large amounts of data yet are not comprehensive in all variables that may be of significant influence. One example is mean household income, which is not directly available through this data. There are measures within the

health factors that may be highly correlated with mean household income, but proper analysis requires appending to the data. In order to analyze the data, the county health factors and outcomes data was appended with mean household income data, population data, as well as information regarding Virginia Department of Health (VDH) jurisdictions. The addition of VDH jurisdictions, which exist in two levels of large and small regions, allows for better understanding of how not only a county is affected but also its neighboring counties are affected. Virginia is comprised of five large health jurisdictions and thirty-five small health jurisdictions, accounting for all 133 counties. Although each of the five major regions contains what may be considered a moderately-sized city, further investigation into the regional impact is necessary especially in comparing rural and urban areas.

Defining the difference between rural and urban is a challenging task. Metrics disagree on what defines these two classifications and what variables, whether they be housing density or financial prowess for example, best characterize them. Different governmental bodies have created methods to classify these two groups and tend to agree on the majority, but there is not uniformity. One approach is to simply rely on one metric to classify these groupings, however this study aims to encapsulate more than one metric's data. Therefore, three metrics were used to classify the different counties into a rural or urban classification: The Office of Management and Budget (OMB) with metro county classification, The United States Census Bureau with metropolitan statistical areas, and Rural-Urban Commuting Area (RUCA) codes. OMB and the Census Bureau classify their data on a county-wide level, providing similar breadth in the data as the county health factors and outcomes data (Office of Management and Budget, 2010). RUCA codes, on the other hand, are determined on a distance-based metric as a branching from OMB metro county classification and are on more of a sub-county level (USDA ERS, Accessed January

21, 2021). This creates challenges with the data, as counties are not binned as rural or urban but are zip code level. To ameliorate this, a method was necessary to convert these zip codes to a county-level metric. For the scope of this study a simple majority of a county was decided to be adequate in classifying whether the county would fall into a rural or urban classification, with the county being classified as urban if the majority of the area was a RUCA code between one and three. Though subjective in nature, this is used along with the other two rural-urban classification metrics and is not alone the determinant of a county's classification.

Further analysis was necessary to understand how variables affect one another. An example of this is the clinical care data which comprises twenty percent of the weight of the county health rankings calculations. Of the clinical care data, access to care is half of this data, calculated from variables such as proportion of uninsured residents within a county. Although we may anticipate mean household income to be correlated with the proportion of residents uninsured, there is reason to investigate how influential of a predictor income is in determination of the proportion of uninsured residents in a county, as it may be different in rural areas compared to urban.

Finally, within the health factors and health outcome data it is important to understand how the counties are distributed compared to one another. The health factors and outcome data is organized by rank-order as well as by z-scores. The z-scores, although a standardized format, are only contextualized within the scope of counties in Virginia rather than a national scope. This is sufficient for this analysis yet limits the ability to generalize exterior to this study. Given there are two different metrics to understand the data, it is important to understand how they interact then analyze the data to see what trends exist between rural and urban jurisdictions. Analysis of the distribution of z-scores for urban and rural jurisdictions was

conducted via two-sample t-tests to provide insight as to whether there is a significant difference between the health outcomes and health factors of residents in either classification. This analysis was carried out using R. With the z-score and ranked data, there is ability to understand if more rural counties fall outside two standard deviations from the state mean in comparison to urban counties, or if the average rural county falls below the state mean compared to the average urban county.

3.2 Primary Survey Data

Data concerning genetics health care will be aggregated through a survey that was distributed online to understand the perceived experiences by individuals using genetics health services in Virginia. To qualify for the study, participants must be residents of Virginia, have participated in genetics health services, and be at least 18 years of age. The survey outlined a number of questions involving area of residence, distance to specialized provider, and wait time until first appointment. Other questions ascertained the perception of the appointment, resources made available, and the overall experience of genetics services (full survey provided in Appendix B). Knowing how limited genetics service providers are, travel time and interpersonal experience are important to consider as they could serve as substantial barriers. This arm of the study aims to find the general anecdotal experiences of patients using current genetics services while attempting to find insight as to where perceived barriers exist as well as where improvements could be made.

The survey was posted in late August of 2020 through multiple avenues. It was primarily shared through family-to-family networks within Virginia, aiming to reach individuals through social networks. The survey was made available through flyer on Facebook and shared with any

pages associated with the network on August 25, 2020. It was also allowed to be shared by members of the community. The flyer was also distributed through the Virginia Commonwealth University's Partnership for People with Disabilities listserv, reaching members of the general community who had previously signed up for information regarding events and research opportunities to participate in. The survey was then finally shared through members of the regional genetics network overseeing genetics services for Virginia and other states, NYMAC. Members of NYMAC shared the flyer with their pertinent communities in an effort to expand the breadth of the word-of-mouth distribution. The survey was available for approximately three months.

4.0 Results

Beginning with the county-level health factors and outcomes data, all 133 counties of Virginia were accounted for and analyzed within the 35 small VDH jurisdictions and the 5 large jurisdictions. The first analysis done was on the highest-level data, the health factors and health outcomes z-score and rankings. Stratification between urban and rural jurisdictions required a county to be uniform in all three metrics to be classified as urban or rural. This stratification is held for all statistical analyses, but the scatter plots depicted do not adhere to this strict classification.

The z-scores and rankings serve as two different methods of showing the distribution, and presented with a correlation coefficient of 0.8154 in urban jurisdictions and a correlation coefficient of 0.9178 in rural jurisdictions. Given these measures are significantly correlated, the more insightful data of z-scores was used throughout the remainder of the analysis.

A scatterplot depicting health outcome z-scores against the mean household income with subclassification by major VDH region showed that an increase in income was correlated to a greater health outcome z-score and is shown in Figure 1.

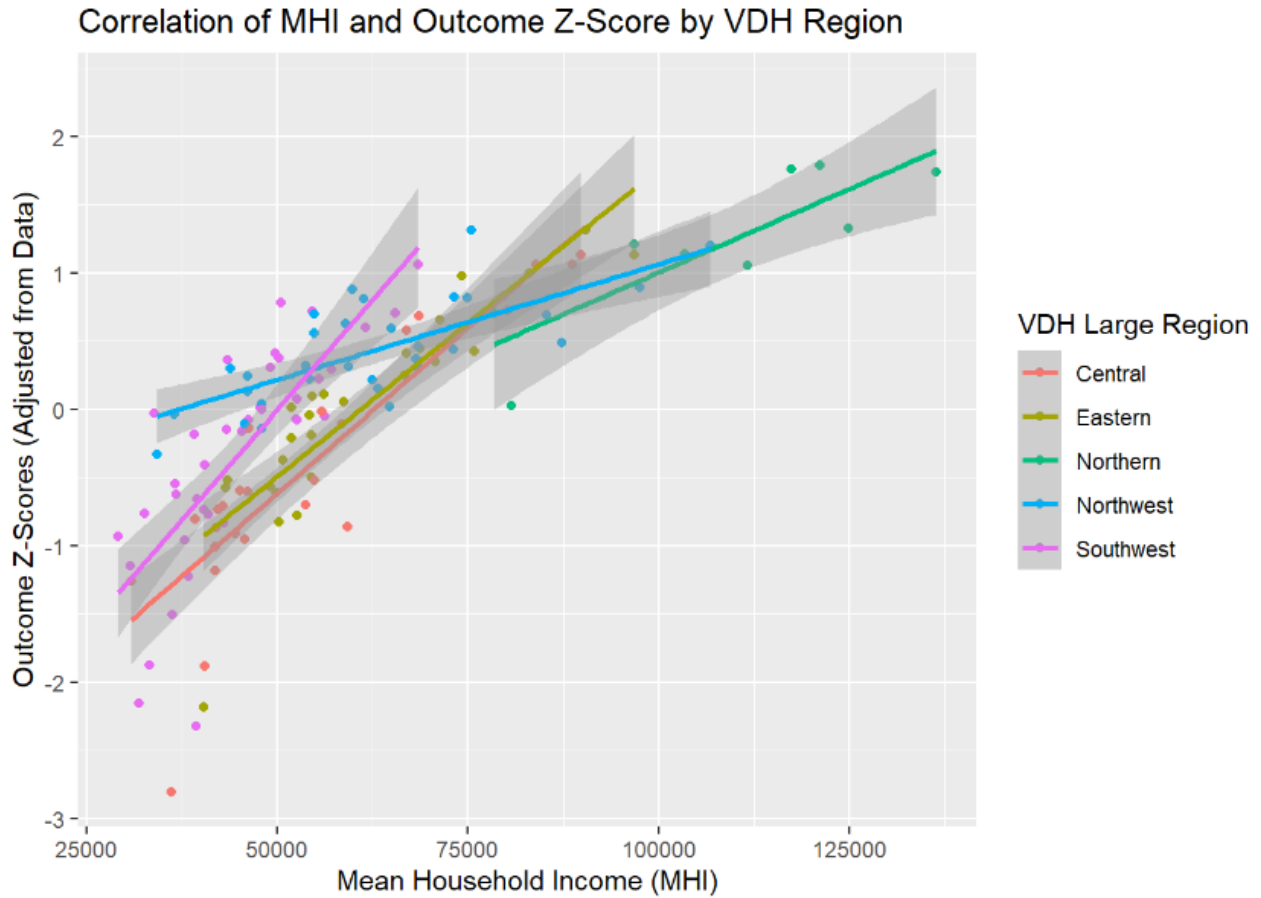


Figure 1 Health Outcome Z-Score over Mean Household Income (2018), by VDH Large Jurisdiction

A plot comparing the distribution of outcome z-scores for rural and urban county classifications is shown in Figure 2. The two z-score groupings exhibited the difference between rural and urban residents within Virginia. Given the two distributions are assumed to be independent, an F test for equal variances for the health outcomes z-scores determined that the distributions have approximately equal distribution ($F=0.68647$, $p=0.1284$). A two-sample t-test was conducted and determined that there is a significant difference between urban and rural counties' mean z-score ($T=-4.372$, $p=0.2486e-05$), or that rural counties on average fall below the average z-score for urban counties. This was similarly analyzed with health factors z-scores. Once again, an F test for equal variance was conducted and found that the variances of the distribution

were not approximately equal ($F=0.5409$, $p=0.01332$) suggesting a Welch two sample t-test. This t-test found that there was also a significant difference between rural and urban counties, with rural counties having lower z-scores on average compared to urban counties.

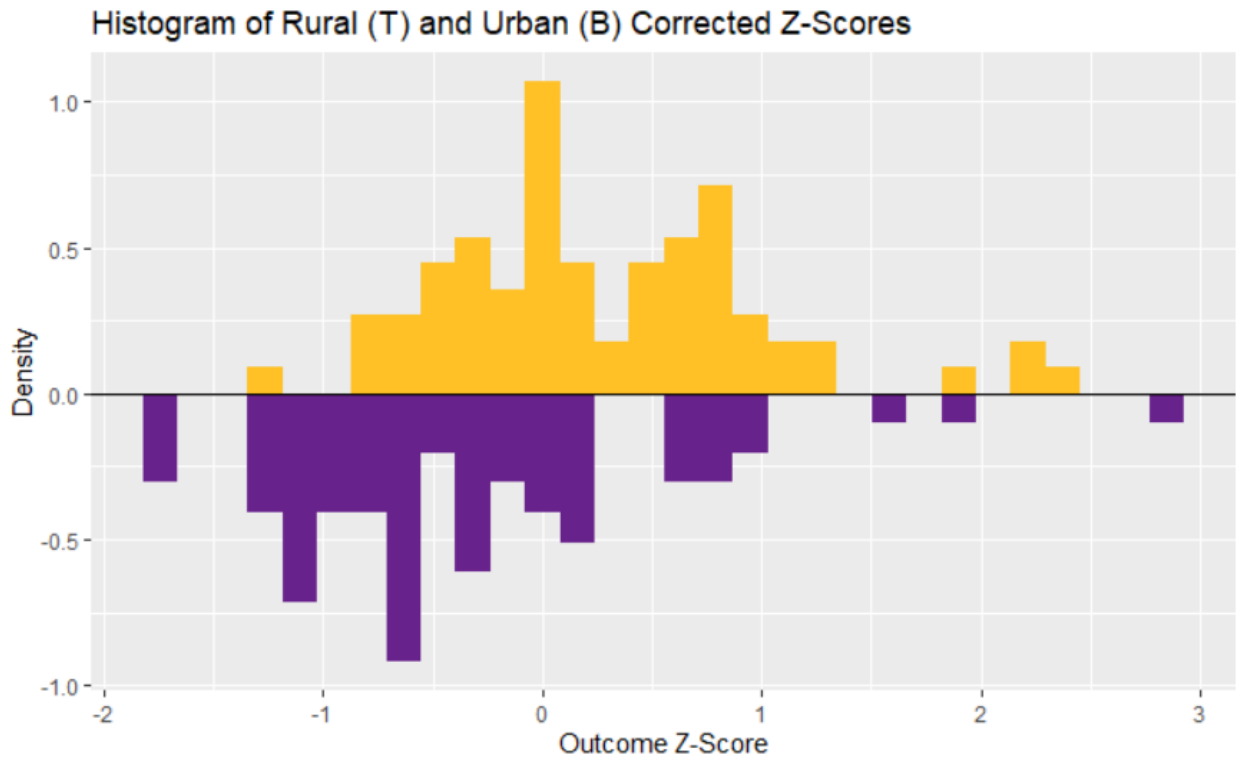


Figure 2 Histogram of Rural (Yellow) and Urban (Purple) Health Outcome Z-Scores

Returning to the ranked-order data, its use is important to provide a more level constraint between all counties. Upon plotting the two rankings against one another it is evident that there is necessity of investigation. Within the urban data, there is a large proportion (25/60) that fall into the upper quartile of both ranking methods. In comparison to the rural data, a considerable proportion (17/71) of these counties fall into the bottom quartile of both rankings. Overall, the 2-dimensional density plots shown in Figure 3 illustrate that the urban counties (3.1) primarily aggregate within the top half of both ranking metrics while the rural counties (3.2) primarily

aggregate in a bimodal distribution around either slightly better than the mean ranking in both metrics or into the bottom-most quartile in both rankings. In short, aggregation of the urban rankings in both factors and outcomes seem to be disproportionately better in comparison to the rural rankings in both factors and outcomes.

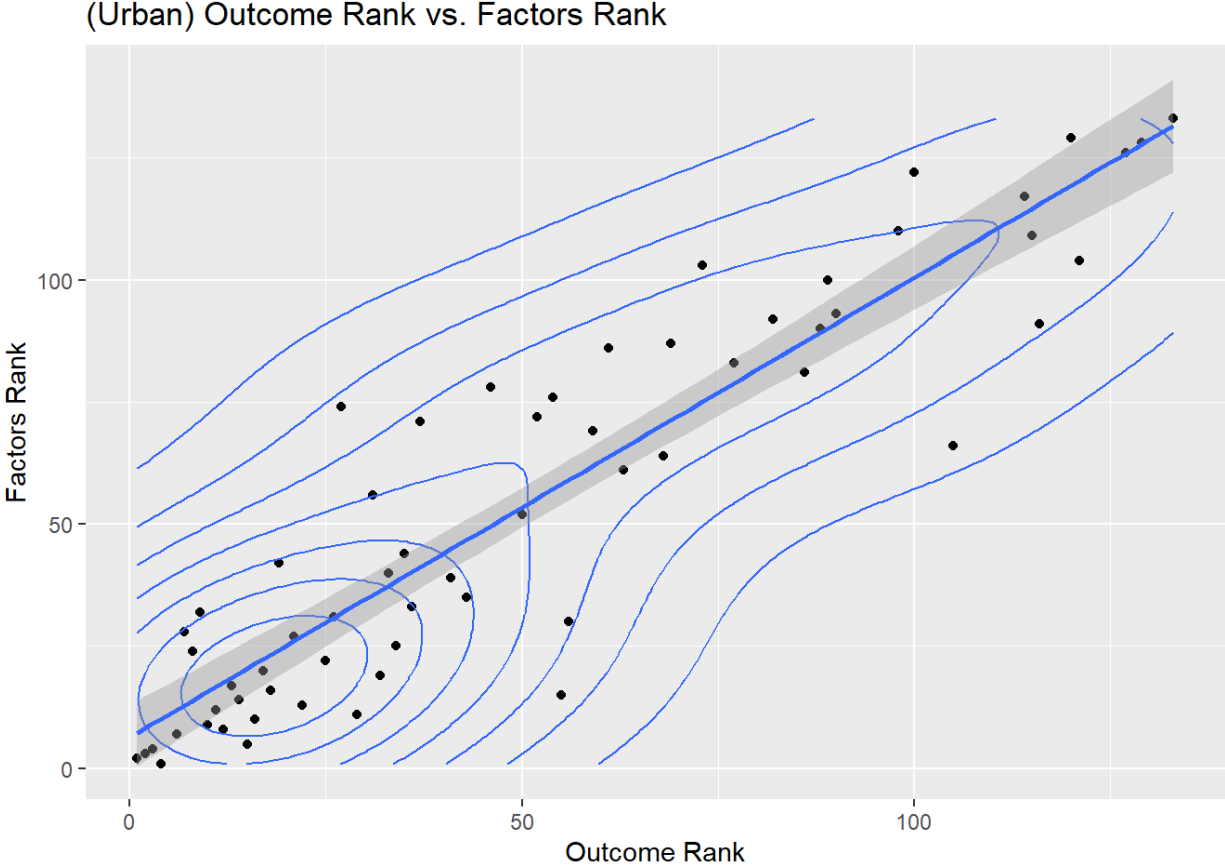


Figure 3 2-Dimensional Density Plot of Urban Outcome Rank Against Factors Rank and Regression

(Rural) Outcome Rank vs. Factors Rank

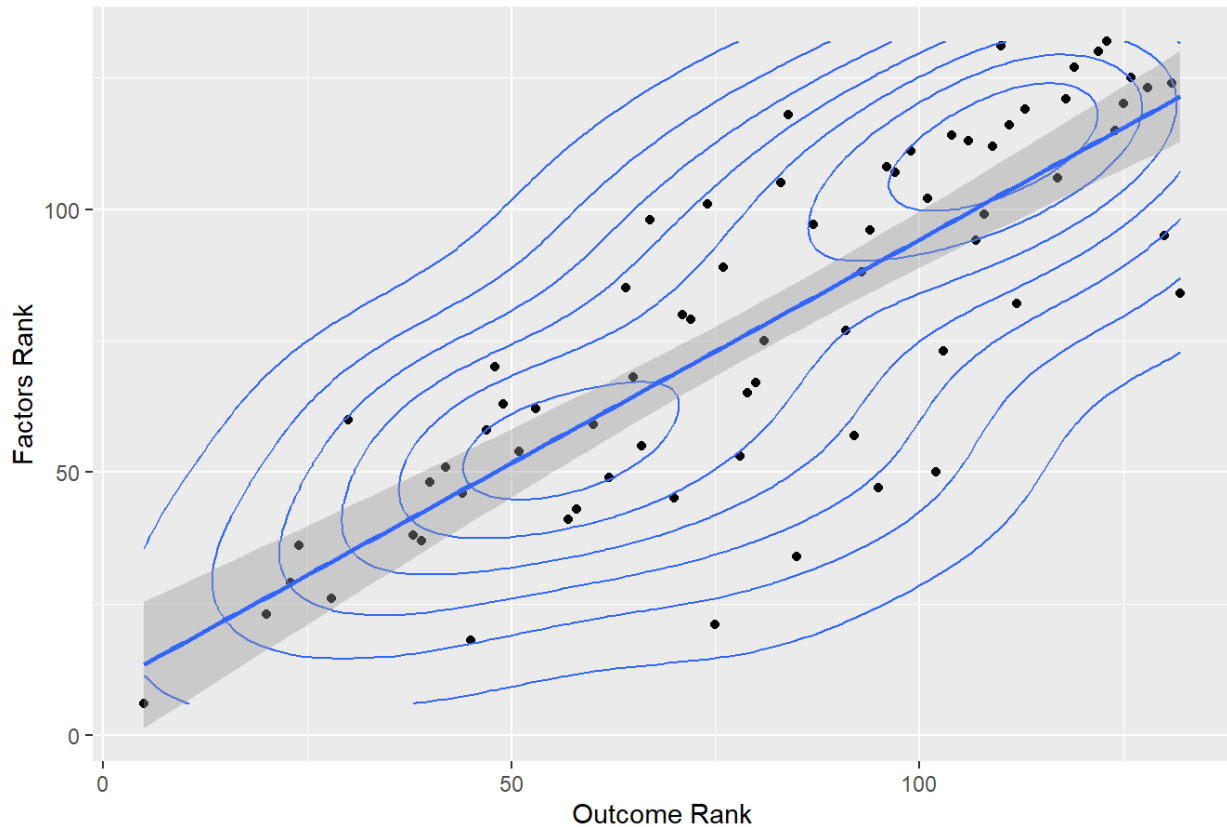


Figure 4 2-Dimensional Density Plot of Rural Outcome Rank Against Factors Rank and Regression

Focusing next upon the mean household income and its relation to the proportion of uninsured residents per county, similar analyses of the distribution were completed. The distribution of the mean household income is shown in Figure 4. The data has a right skew, but F tests for equal variance were conducted finding that the variances were approximately equal ($F=0.2015$, $p=5e-7$). A two-sample t-test was then conducted and found a significant difference between the mean of the urban county mean household income in comparison the rural county's mean household income ($T=-5.95$, $p=3.86e-8$). Identical analyses were done on the proportion of uninsured residents between the two jurisdictions, with an F test suggesting equal variance ($F=0.761$, $p=0.3611$) and a two-sample t-test finding a significant difference in the average

proportion of uninsured residents within rural counties in comparison to urban counties (T=4.321, p=3.64e-5).

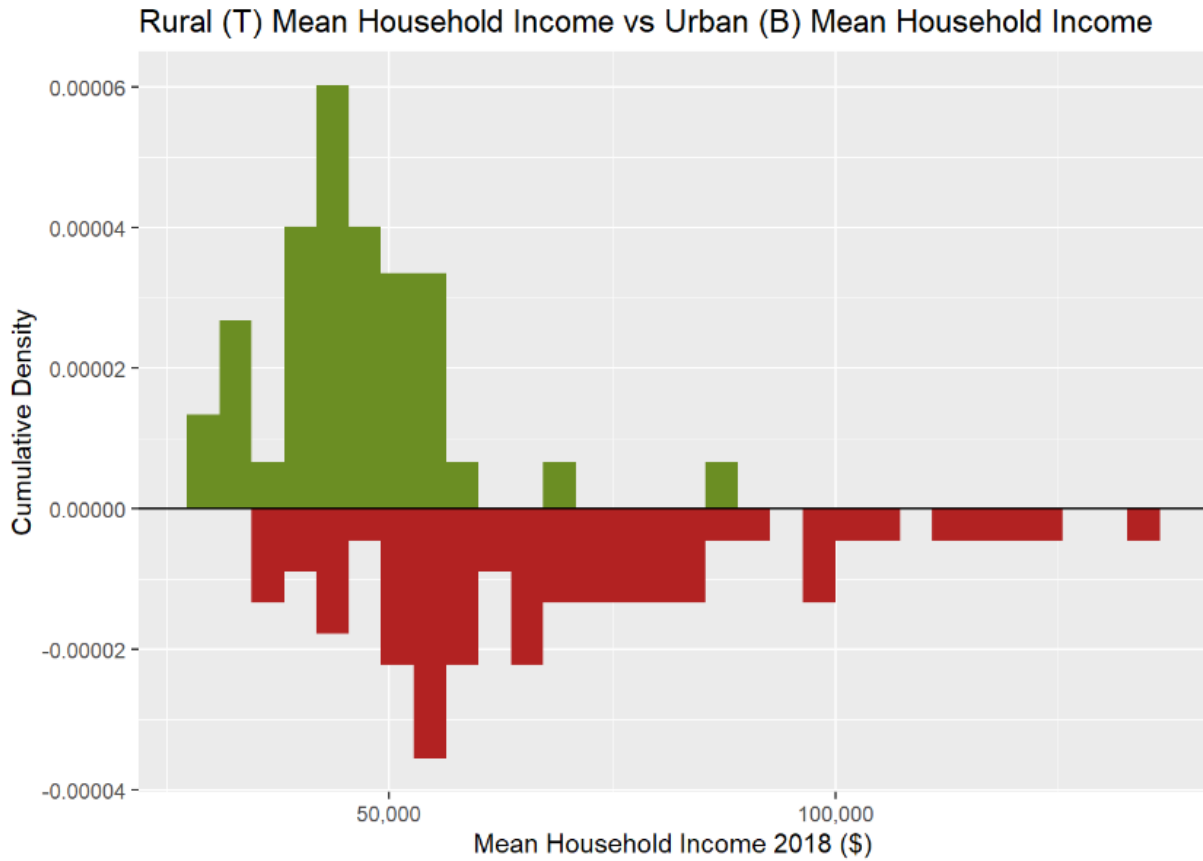


Figure 5 Histogram of Rural Mean Household Income Compared to Urban Mean Household Income

Analysis of correlation coefficients between urban and rural jurisdiction shows a difference in the impact of mean household income on proportion of residents uninsured within a county. Urban jurisdictions have a correlation coefficient of -0.05602 ($p=2.2e-6$), while rural counties have a correlation coefficient of -0.3207 ($p=0.041$). Both show a trend of mean household income as a significant predictor of proportion of uninsured residents, yet the impact is of a lesser magnitude in rural counties.

4.1 Survey

The survey was opened by a total of six participants, with only five providing responses. Of those five, one did not complete all questions, however their responses were retained. The respondents were overwhelmingly female, between 36-45 years old, non-Hispanic white, and received a master's degree. Importantly, all participants resided within what would be classified as an urban county. A full breakdown of the demographic data obtained is shown in Figure 5.

<i>Variable</i>	<i>Category</i>	<i>N</i>
Sex	Male	1
	Female	4
Age	18-25	
	26-35	
	36-45	4
	46-55	1
	56-65	
	65+	
Race	Black/African American	
	White/Caucasian (Non-Hispanic)	3
	White/Caucasian (Hispanic)	1
	Asian	1
	American Indian/Alaskan Native	
	Other	
Respondent	Self	2
	On Behalf of Dependent	3
Education	Some High School	
	High School	1
	Trade School/Associate's	
	Some College	
	Bachelor's Degree	
	Master's Degree	4
	PhD or Higher	
Prefer not to Answer		
Residence	Urban	4
	Rural	0*

Figure 6 Demographic Breakdown of Survey Participants

*Residence category shows one less participant due to subject drop-out of survey

The participants reported that there were multiple challenges and barriers faced, with the largest being the wait-time until first appointment. Though they all resided in urban counties, they reported a wait-time of 1-3 months for their first appointment and an average travel time of 45 minutes to reach their appointment. They were mostly satisfied with their initial visits, however the majority responded that they were dissatisfied with mental and emotional support provided.

In terms of perception of services, most participants self-reported a very good level of health literacy with comfortability with genetic concepts by rating themselves as an average of five out of seven on a Likert scale. When asked their familiarity with common health terms and common genetic terms, both reported less comfortability in both categories. There were only three participants who answered the questions pertaining to if they felt their needs were met, with two agreeing their needs were met and one disagreeing that their needs were met through genetic services. The participants were also asked about the use of telehealth in the future (both in regards of their perception of it and their internet's ability to support such a demand) with all participants responded they could use telehealth appointments and had the resources to do so.

The end of the survey contained an open-ended question asking the participants if there was information they felt would be beneficial to the study about their experience or perception of genetics services that was not asked about. Only one participant completed this question, but their anecdotal evidence contained valuable data regarding the challenges they faced. The most explicitly listed issues encompassed long wait-times for initial appointments, a lack of understanding why they were meeting with genetic professionals, how little valuable information was provided throughout the process, and that the aggregate monetary and time costs were too great.

5.0 Discussion

5.1 County-Level Data Discussion

This data illustrates persistent trends when comparing urban counties to rural counties, or more generally, urban communities to rural communities. The results outline how both within the ranking or z-scores there is a consistency of urban counties being above the mean while rural counties fall below the mean. This is consistent with previous reports indicating that health disparities exist between urban and rural areas (Van Dis, J., 2002; North Carolina Rural Health Research Program, 2017). Though highly colinear, there are variations between the measures. The use of z-scores would provide a more normal distribution to encapsulate the data especially as it is specified to the state of focus. When partitioning the data into rural and urban jurisdictions, the data found that although approximately equal in variance both the health factors and health outcomes were significantly different. This provides insight prior to further analyses that the overarching outcome measures exhibit this disparity, warranting further understanding.

The mean household income analysis provides important information due to socioeconomic status being an influential predictor of health care outcomes. This information is also consistent with prior as lower income and rural residents have a trend of worse healthcare outcomes compare to urban residents (North Carolina Rural Health Research Program, 2017). Higher levels of income permit more agency and choice in health care decision making, especially as additive variables such as insurance are considered. The data found a significant difference in mean household income between rural and urban counties, with rural counties being more likely to fall into lower income brackets. This analysis does have limitations, including that the data may

be skewed more heavily towards urban counties such as Arlington city and Loudon city, two of the wealthiest counties not only in Virginia but within the United States. This also has its own skew within rural counties, as the population in some only accounts for 0.02% of the state's population or has less than 10,000 residents. Altogether, mean household income provides valuable insight prior to evaluating proportion of residents uninsured.

Pertaining to the proportion of residents uninsured, the analysis showed once again that there was a significant difference between urban and rural counties. Prior studies corroborate this, as prior studies found more opportunities for insurance in urban areas compared to rural areas (Pateman, 2011). This is also furthered by prior studies that showed rural residents were offered less benefits compared to urban residents, leading to higher out-of-pocket expenses (Hartley, Quam, & Lurie, 1994). Although most the counties range between eight and fifteen percent uninsured, there is still a difference between the two types of counties. The challenge with this data is it being a proportion metric, meaning that although it has been standardized it confines the data to an integer-based system. It is possible to calculate the proportion of uninsured with more informative data, however the US Census data was deemed adequate to understand the general trends. When assessing the conditions for two sample tests, the next issue arises with this data as the integer-based system has potential to violate normality. Regardless, a simple test for normality showed the data to still be approximately normal and not raise concerns.

The proportion of uninsured residents provides valuable insight to what challenges residents may face in terms of payment for health care. As studies have shown (MACPAC, 2018) lack of insurance coverage to be a large contributing factor to declining health, this may help explain why there are poorer health outcomes within uninsured rural residents. However, the data

illustrates that the proportion of uninsured residents in a county is more significantly predicted by mean household income for urban residents compared to rural residents. Mean household income still assists with prediction of uninsured residents for rural residents, but the correlation coefficient suggests there is more data that is necessary to explain proportion of uninsured residents.

Lack of insurance and monetary resources are not the only influential variables that present as a barrier. Others to consider are travel time to a specialist, or even simply to primary care provider, as physical distance may create a lower likelihood of individuals from seeking care. Another that may be important to consider is time until first appointment, particularly if a specialist has a long wait time for new patients, preventing those patients from being able to adequately access the care they need. Though these two trends may not fully explain the differences between rural and urban counties, they may be incredibly informative overall.

The correlation between mean household income and proportion of uninsured residents also reveals some other points of investigation. Though the two variables pass visual tests of normality, there are some points that suggest further investigation. Within the rural strata, most points fall within the lower end of the data but one point, which lies on the upper end of mean household income. This point may not necessarily alter the trend of the data, but it still seems to be an outlier within the majority of the two data sets as it deviates from the rest of the rural grouping. The urban data instead has a consistent spread, with multiple points at the upper end. Both strata show some points that significantly deviate from the mean in terms of being higher in proportion of uninsured residents but are balanced out throughout the data set by multiple points just below the mean. Overall, both trends are informative yet still suggest more data must be considered.

When considering this with how VDH groups their health jurisdictions, these groupings of data, particularly below the mean, may be illustrative of how counties are interacting with one another as a community. An example of this would be Hampton Roads, the southeast portion of Virginia. A resident of this community could reach at least seven different cities in accessing health care. There are differences between the counties, but they interact with one another and residents may cross county lines to access care. Given this, there may be clustering of data within access to care since the residents may cross from one county to another (e.g., Virginia Beach to Norfolk) to receive their care. Further investigation into how these communities exist and provide consistent care to residents would give insight to how residents get their needs met, further understanding the difference between isolated and rural communities and the urban counties that fall below the mean in this regression analysis.

5.2 Survey Data Discussion

The survey data provided further insight to the trends in genetics services but was limited due to sample size. The data was fully comprised of urban residents and outlined persistent barriers concerning the wait-time to first appointment, as well as travel time to appointment. This challenge with travel time was surprising as all respondents were within relative proximity to a genetics provider, but previous anecdotal evidence within family-to-family networks has indicated that the nearest provider is not always the provider an individual or family may use. Instead, they may need to search for providers that are further away to get an appointment within this 1-3 month time frame. The universal support of telehealth is not as surprising. Given the rollout of this survey in the midst of the COVID-19 pandemic, it is understandable that participants were more open or

willing to rely on this medium for appointments. Satisfaction with telehealth has been shown before the pandemic (Buchanan et al., 2015), so it could easily persist once restrictions eventually lift in totality. Regardless, they all felt it would be a mechanism to reduce wait-time until first appointment and reduce barriers in traveling to a particular provider.

The participants did believe their needs altogether were mostly met, yet also supported the point that their mental and emotional support was lacking through their provided services. It is challenging to quantify the level at which their needs are not being met, but this self-report data is still illuminating regarding the opportunity for improvement within services provided (Yildirim, A., et al., 2013). A potential effort could be made to provide extra mental and emotional support, or even link them to a family-to-family network that may provide them the desired support and assistance. Providing multiple options would be beneficial as a unilateral approach would not meet the variety of needs.

Their self-reported health and genetic literacy is mostly transparent. The participants did not report to be experts, nor did they report they were totally unaware of the concepts discussed. When asked about comfortability with explicit terms in health and genetics, the self-reported level dropped to the next lowest level. This is important as most participants have completed a master's degree. If individuals have completed that level of education yet still lower their self-reported comfortability with health terms, there is the possibility that they have a general understanding of them rather than a deep-level understanding. The difference between these creates challenges, especially as they are likely to be overwhelmed with novel information throughout the process of discovering a genetic condition and is only exacerbated by mental and emotional challenges. This challenge is faced by individuals holding a master's education and higher, but only a small proportion of the United States population has a similar level of education. There must be useful

information not only made for individuals with this level of education, but also for individuals who have only completed a high school degree or GED. Overall, the generalizability of the complex information is of concern.

Finally, the anecdotal evidence provided by the single participant illustrates the multiple challenges yet to be overcome in genetics services. Individuals receiving a genetic diagnosis deal with numerous challenges, and their reception of services should not be creating more barriers or complications. To hear a participant state one challenge being their misunderstanding of why they are even meeting a specialist or genetic professional is indicative that educational efforts are not reaching their goal. This is only furthered by the same participant stating that they received little information of value. It shows the challenges that must be further understood and removed to assist those affected by all forms of genetic conditions.

5.3 Limitations

There are many limitations to this research methodology. The first and foremost of this data is the population-level focus of it, rather than more individual-based information. It provides insight to what residents experience within a county, but it is not sampling to determine significant differences between the populations and yielding more concrete conclusions. There is also the great challenge in defining the two types of counties. Using three different metrics allows for flexibility but also removes the variability that exists when part of a county is not strictly urban or rural. The definition of rural and urban was not an incredibly stringent one, but simply relying on correlations between three pre-existing sources. A novel, multifactorial model may be better in classifying the urban and rural areas, but it still does not adequately evaluate the in-between

counties that are debatably skewed to either classification. Another significant limitation is the data, particularly the z-scores and mean household income data. The z-scores are standardized within the state of Virginia yet are a standardization that combines either two variables (each found through complex calculations), or a weighted model that attempts to join a vast list of variables. Focusing more directly upon data, such as mean household income and its connection to proportion of uninsured residents, provides more direct insight. However, even the use of mean household income creates a challenge as taking an average of means skews the data towards a kurtotic distribution. A transformation of some kind may be helpful in future research to account for this limitation, but after consulting a statistician they argued that since it is the independent variable the distribution should not be too influential given its proximity to a normal distribution. This also connects to the distribution of proportion of uninsured residents, as that is constructed on an integer-based system, with only one point between each whole value. This removes some refinement in the data, but the general trends can still be elicited even within the stepwise function seen in this study.

Another instance of data refinement being lost is within the income data, or the use of mean household income rather than median household income. Mean household income may be informative but can be heavily skewed when there are significant outliers. An instance of this may be within Loudon County, which is commonly referred to as the wealthiest county in the United States due to the large number of international delegates and government officials residing in the county. This is not to say that all the residents are wealthy, but that a select subset of the county are wealthy, changing the perception of the average Loudon County resident. A more informative point of data would have been median household income, which removes this skew. In future

analyses of this data, use of median household income would provide a more powerful insight into differences between urban and rural counties.

One final limitation that affected the county-level data is the spread over counties. Within the background the major regions of Virginia were discussed and how there are major cities within each of the VDH regions. The county lines are not uniformly drawn around these different cities. One example is the city of Lynchburg. This city is not an enclave within a county, like Charlottesville, but instead is located at the junction of three different counties: Amherst County, Bedford County, and Campbell County. The presence of Lynchburg at these three counties' junction means that the surrounding areas of Lynchburg are not defined by one county's ranking, z-scores, or individual variables, but that it is spread throughout these three counties. In essence, the county-level variables do not adequately account for the difference between county and community, which warrants further research and investigation. If the data was able to cover both variables, there may be much more insightful data to evaluate. This challenge is only exacerbated by changes over time concerning the counties and this data. One example is the city of Bedford, which no longer exists as the population has declined below the threshold and it became a town consolidated within Bedford County. The current county-level data has changed over the years, potentially losing some intricacies that may be informative such as the counties where these changes have occurred. Nevertheless, it is fair to argue that an overall refinement would assist in understanding the trends better.

The survey proportion of this study had several important limitations. The most glaring issue is the lack of responses, only accumulating four fully completed surveys. This low response rate may be due to a number of potential factors, such as the decreasing response rate in surveys throughout recent years, as well as competing priorities that may divert attention away from

research tasks. One team member from the family-to-family network hypothesized that the rollout of the survey occurred too closely to the beginning of schooling, so any participants responding on behalf of dependents under the age of 18 may have had other matters to concern themselves with than a survey. It is also a large limitation of the survey that all the respondents were residents of urban areas, as the aim was to compare urban residents to rural residents. Without a single observation in the rural counties, it is inappropriate to extrapolate the data outside of the confines of rural residents. However, even with this limitation it is not impossible to hypothesize that the pre-existing barriers to healthcare are exacerbated within specialized healthcare, such as travel time to appointment.

Another large limitation to the survey was its rollout. There was a limited availability to promote the survey through targeted intervention. Instead, the survey was shared with the communities connected to the family-to-family network. The survey was ultimately shared to social media pages that had an excess of 3800 followers and an email listserv, but only yielded a total of four full responses. The limitation of the rollout could have been mitigated by coordination with other institutions, governmental agencies, or other family-to-family networks, yet the scope of the efforts for this study did not permit that. The survey could also have benefited from inter-university rollout, not confining itself to being affiliated with one university's existing network. Even connecting to other Virginia institutions for rollout may have assisted in the response rate, which would be worth exploring in another iteration of this investigation.

The final stark limitation to the survey was the confined nature of the responses. The survey was designed to have a Likert scale style, with respondents having the opportunity to rate their agreement from highly disagree to highly agree on a range of seven points. There was only one question that permitted an open response, where only one participant provided a response. A more

apt approach to understand the perceptions and experiences of these individuals and families may be a more qualitative approach such as a focus group or a larger number of open-ended questions. With the confinement to a Likert scale and translation of experiential data to quantitative values, there is significant chance of losing valuable data on what participants have encountered through their use of genetics services.

Other limitations do exist within the overall structure of this study. One that has been briefly considered is how counties do not entirely encapsulate all variables of data, such as intercommunity interactions or residents that commute into urban centers. There were efforts to consider the value of this information with the use of RUCA codes, which does consider commuting into urban centers, but it still does not present a solution to intercounty interactions. One hallmark example of this is the City of Lynchburg, which sits upon the junction of three counties and exists as an independent city as was previously mentioned. There is considerable information lost with these types of communities, as an individual may work in one county, reside in another, and have a healthcare provider in a third. This cannot be effectively understood without having adequate understanding of the communities and subcommunities that exist within each county and neighboring counties. Even with this form of approach, a state-wide analysis may create too complex of a model to understand without fully understanding the principal components.

Overarching the entirety of this investigation, the three aims of this paper were met. Primary targets of influential factors within health care were understood at a deeper level, with the partition between urban and rural residents showing how each population has their own burden to bear. The second aim was accomplished by unveiling the problems and barriers inundating the specialized sector of health services, with survey participants outlining how they have been apprehensive due to these barriers. The final aim was achieved by understanding how each strata

of barriers are not totally independent but magnify in influence by interacting with one another. One such example could be a rural resident who is more likely to have a lower mean income and less likely to have insurance coverage, who then must combat the issues of long time-to-first appointment for a provider that is more than an hour drive away. These barriers only continue to pile onto residents who seek to have their needs met.

Mitigation strategies partially exist for many of these barriers. The existence of social media groups has permitted a more accessible form of peer education, not only relying upon health care providers to inform the public. Telehealth and telepractice has flourished throughout the pandemic, and its use can be adapted for future endeavors in outreach to underserved communities. However, these are not foolproof methods that can be applied to any community. Communities are unique and have specified needs, many of which are not directly transferrable even to their neighbors. Public health entities and agencies must recognize the issues that affect the current landscape of Virginia, developing plans that are tailored to each community and enact them. Without this form of area-tailored approach, the barriers that were outlined in the two arms of this investigation cannot be wholly removed. One form of improvement may be to involve multiple mitigation strategies into a single, cohesive approach. This may function as a virtual seminar for families to attend that is held by a health care provider, or even as a telehealth clinic that is established on one day of the week to provide services for remote residents. Strategies like these have their own impediments, but the opportunities still exist for improvement. It simply takes one collective push in the right direction to spur a movement, no matter the size.

6.0 Conclusion

This study found significant differences between rural and urban counties as defined by three different area classifications. Between two forms of connected data, they tend to be highly correlated and show the fact that urban counties tend to be above the median while rural counties tend to be below the median of health rankings for the state, supporting previous research in other communities (North Carolina Rural Health Research Program, 2017). Urban counties tend to outperform their rural counterparts in mean household income, health factor and health outcome ranking, as well as standardized health scores within state borders. There was also evidence that rural counties were more commonly ranked in the bottom quarter of both health outcomes and health factors, while urban counties were more likely to be above the median in both classifications. As rural residents have been shown to be at a significant disadvantage compared to urban residents (Johnson et al., 2006; Heady, H., 2002), this analysis suggests specific areas in which they are disadvantaged in the context of Virginia. These results provide insight as to what key details could be targeted in public health mitigation efforts for all rural residents rather than within specified health care services, specifically access to insurance and how an increase in income alone does not rescue any deficits experienced by rural residents. This research could also inform public health agencies and health care providers in others states that are comprised of similar rural populations.

The survey data illustrated that barriers persist within genetic services, even as mitigation strategies such as telehealth have become more prevalent in recent years. Urban residence for the respondents of this survey did not provide a short time to first appointment, nor did it provide a short travel time to provider. Survey respondents also outlined the complexity of information, as

patients with higher levels of education still struggled with understanding core genetic concepts. Cohesive efforts must be made to make genetic services accessible in a timely manner and comprehensible by all education levels. Using avenues such as telehealth and family-to-family networks with families that need genetic services would assist in providing the educational support, mental/emotional support, and provide the services within a timely manner.

**Appendix A Exempt Determination of Genetics Healthcare Study by University of
Pittsburgh Institutional Review Board**



EXEMPT DETERMINATION

Date:	July 17, 2020
IRB:	STUDY20060002
PI:	Andrew Weko
Title:	Experience of Genetics Healthcare Study for Virginia Residents: A Mixed-Methods Approach
Funding:	None

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:	7/17/2020
Exempt Category:	(2)(iii) Tests, surveys, interviews, or observation (identifiable); and for which limited IRB review was conducted via expedited review

Approved Documents:	<ul style="list-style-type: none"> • Experience of Genetics Healthcare Survey (Full Survey) • Interview Guideline.docx • Survey linked for submission of email (ensures no linkage of survey and interviews) • Advertisement for Survey to be posted in groups and into listserv • Email Draft.docx • Exempt Application Form with Edits Regarding Identifiable Information • Script of Informed Consent for Genetics Healthcare in VA Survey.docx
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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/>.

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, [Emily Bird](#).

Please take a moment to complete our [Satisfaction Survey](#) as we appreciate your feedback.

Appendix B Experience of Genetics Healthcare Survey

Experience of Genetics Healthcare Survey

Start of Block: Default Question Block

Informed Consent This is a research study being managed by researchers at the University of Pittsburgh Graduate School of Public Health and is being distributed through Virginia Commonwealth University's Partnership for People with Disabilities network. They are focusing on the current state of healthcare and how to improve it in the Commonwealth of Virginia. Taking part in this survey is voluntary. There are no negative outcomes for not completing this survey, and there is no compensation for completion. Participants will not be paid. You can also withdraw from the study if you no longer wish to participate. We want to hear from households that have taken part in genetics healthcare services. You must be at least 18 years old to participate. Genetics healthcare is a growing field. Genetics involves studying family history of illness and health to see what trends exist. Research has shown the connection between personal health and genetics. Involving genetics in general healthcare has become more common as technology improves. It is commonly involved in certain healthcare fields like cancer genetics, prenatal genetics, and genetic counseling. This knowledge of your family history can serve as a way for doctors to better predict your own health concerns. Options for genetics healthcare exist in Virginia, but the higher demand recently has shown there is room for improvement.

This survey will ask you many questions. We want to hear from households that have experienced genetics healthcare services. You must be at least 18 years old to participate. Some questions will include demographic information to let us know who is completing this survey. It will also ask where your household has received genetics healthcare and what your experiences were. This survey will ask about the challenges faced with this field, and your thoughts on moving into fields like telehealth (virtual appointments with a professional). Finally, this survey will also ask about health literacy and interest in genetics healthcare. Once completed, researchers will review the data. They will combine it to make sure no personal information can be traced back to anybody. The data will be saved on secured servers at the University of Pittsburgh. All survey data will be recorded anonymously and will not be identifiable when the data is shared. The study will be shared with other professionals in the field of healthcare and public health. This will help them know how to best meet your needs in the future. The survey will take roughly 15 minutes to complete. The largest risk with this study is breach of confidentiality. We aim to avoid this by keeping any data collected on secured servers. Participation in this survey will not affect your connection to VCU's Partnership for People with Disabilities. They will have no way of knowing who participated. At the end of the study, you will have the option to choose to be in a follow-up interview. These interviews will be done with the research coordinator and recorded. Once the research coordinator creates a de-identified transcript, the recordings will be deleted. The interviews will be fully

de-identified and all data put together to minimize risk of identification. This data will also be stored on the secure servers but in a different location to ensure no data can be linked. The same risks of the survey data apply to this data. There is risk of breach of confidentiality, but the risks are slightly higher since this is identifiable data. However, de-identification will immediately follow and it will be kept on a secure server to minimize risk. There is no compensation or payment for participation in this part of the study. Not participating in this section of the study will not affect your data for the survey portion. It will also not affect your standing with the Partnership for People with Disabilities. Any further questions can be sent to the study coordinator, Andrew Weko, at atw40@pitt.edu. Thank you.

IC Agreement By answering yes below you are agreeing you have read the text above. You are also agreeing that you are at least 18 and all the information you provide is accurate.

- Yes, I have read the informed consent above and am at least 18 years of age (1)
- No, I have not read the informed consent above or am not at least 18 years of age (2)

Skip To: End of Survey If By answering yes below you are agreeing you have read the text above. You are also agreeing that... != Yes, I have read the informed consent above and am at least 18 years of age

Page Break

1 What is your sex?

- Male (1)
 - Female (2)
 - Intersex (3)
 - Prefer not to answer (4)
-

2 How old are you?

18 - 25 (1)

26 - 35 (2)

36 - 45 (3)

46 - 55 (4)

56 - 65 (5)

65+ (6)

3 What is your ethnicity or race?

Black or African American (1)

White or Caucasian (Non-Hispanic) (2)

White or Caucasian (Hispanic) (3)

Asian (4)

American Indian or Alaskan Native (5)

Other (6) _____

4 What is your highest level of education completed?

- Some High School (1)
- High School (2)
- Trade School/Associate's Degree (3)
- Some College (4)
- Bachelor's Degree (5)
- Master's Degree (6)
- PhD or Higher (7)
- Prefer not to answer (8)



5 What is your zip code?

6 Who in your household receives genetics healthcare?

(If there are multiple in the same household, we would appreciate a submission of the survey for each person)

- Self (1)
 - Spouse/Partner (2)
 - Child/Dependent (3)
 - Other member residing in household (4)
-

7 Are you aware of a history of genetic conditions within your family? This is not limited to just your household.

- Yes (1)
- No (2)
- Unsure (3)

Skip To: 9 If Are you aware of a history of genetic conditions within your family? This is not limited to just... != Yes

8 How many people in your family have been diagnosed with a genetic condition?

1 (1)

2 (2)

3 (3)

4 (4)

5+ (5)

Page Break

9 Throughout this section, the person receiving genetics healthcare services will be listed as "you."

Roughly when did you start genetics healthcare services?

Enter Date:

10 What city and health system do you usually get your genetics healthcare services from?

Examples:

Norfolk, VA - Sentara,

Charlottesville, VA - UVA Health,

Durham, NC - Duke Health

11 Are most of your appointments outside of Virginia?

Yes (1)

No (2)

12 What type of genetics healthcare services do you receive?

- Adult Genetics (1)
 - Cancer Genetics (includes cancer risk assessment, screening or prevention; hereditary/familial cancer) (2)
 - Cardiovascular Genetics (3)
 - General Genetics (includes Medical Genetics and Birth Defects) (4)
 - Genetic Counseling (5)
 - Metabolic (6)
 - Neurogenetics (7)
 - Pediatric Genetics (8)
 - Prenatal Genetics (includes prenatal diagnosis, antenatal testing, and perinatal genetics) (9)
 - Reproductive Genetics (includes preconception genetic services) (10)
 - Other (11) _____
-

13 What are the biggest hurdles in getting an appointment with a genetics provider?

14 Roughly how long did you wait for the first appointment? (Example: 2 Months and 2 Weeks)

Month(s) (1) _____

Week(s) (2) _____

15 Based off your wait time, how much do you agree with the statement "I was satisfied with the wait time for my first appointment"?

Strongly Disagree (1)

Disagree (2)

Somewhat Disagree (3)

Neither Agree nor Disagree (4)

Somewhat Agree (5)

Agree (6)

Strongly Agree (7)

16 How long was the typical travel time to get to a genetics appointment?

- Less than 30 minutes (1)
 - 30 - 60 minutes (2)
 - 1 - 1.5 hours (3)
 - 1.5 - 2 hours (4)
 - 2 - 2.5 hours (5)
 - 2.5 - 3 hours (6)
 - 3+ hours (7)
-

17 Have you ever had genetics healthcare services through telehealth? This includes virtual meetings or appointments.

- Yes (1)
 - No (2)
-

18 Rate your agreement with this statement: "My internet connection is strong enough for a healthcare appointment through telehealth."

- Strongly Disagree (1)
 - Disagree (2)
 - Somewhat Disagree (3)
 - Neither Agree nor Disagree (4)
 - Somewhat Agree (5)
 - Agree (6)
 - Strongly Agree (7)
-

19 How would you rate the first visit with the genetics professional?

- Extremely Dissatisfied (1)
 - Dissatisfied (2)
 - Somewhat Dissatisfied (3)
 - Not Satisfied or Dissatisfied (4)
 - Somewhat Satisfied (5)
 - Satisfied (6)
 - Extremely Satisfied (7)
-

20 How would you rate the emotional and mental support provided in your visits?

- Extremely Dissatisfied (1)
- Dissatisfied (2)
- Somewhat Dissatisfied (3)
- Not Satisfied or Dissatisfied (4)
- Somewhat Satisfied (5)
- Satisfied (6)
- Extremely Satisfied (7)

Page Break

21 The next questions involve healthcare, specifically with genetics.

How would you rate your own health literacy?

- Very Poor (1)
 - Poor (2)
 - Somewhat Poor (3)
 - Neither Poor nor Good (4)
 - Somewhat Good (5)
 - Good (6)
 - Very Good (7)
-

22 How would you rate your ability to understand medical terms related to health? Think about words like defect, positive test result, and syndrome.

- Very Poor (1)
 - Poor (2)
 - Somewhat Poor (3)
 - Neither Poor nor Good (4)
 - Somewhat Good (5)
 - Good (6)
 - Very Good (7)
-

23 How would you rate your ability to educate somebody else about medical terms related to health? Think about words like defect, positive test result, and syndrome.

- Very Poor (1)
 - Poor (2)
 - Somewhat Poor (3)
 - Neither Poor nor Good (4)
 - Somewhat Good (5)
 - Good (6)
 - Very Good (7)
-

24 How would you rate your ability to understand genetics terms related to health? Think about words like gene, protein, and mutation.

- Very Poor (1)
 - Poor (2)
 - Somewhat Poor (3)
 - Neither Poor nor Good (4)
 - Somewhat Good (5)
 - Good (6)
 - Very Good (7)
-

25 How would you rate your ability to educate somebody else about genetics terms related to health? Think about words like gene, protein, and mutation.

- Very Poor (1)
- Poor (2)
- Somewhat Poor (3)
- Neither Poor nor Good (4)
- Somewhat Good (5)
- Good (6)
- Very Good (7)

26 Have you or anybody in your household done direct-to-consumer testing, such as 23andMe, Ancestry, or FamilyTree?

- Yes (1)
 - No (2)
 - Unsure (3)
-

27 How would you rate your agreement with this statement: "It is important to know a family's risk of a genetic condition or disorder."

- Strongly Disagree (1)
 - Disagree (2)
 - Somewhat Disagree (3)
 - Neither Agree nor Disagree (4)
 - Somewhat Agree (5)
 - Agree (6)
 - Strongly Agree (7)
-

28 How would you rate your agreement with this statement: "Genetics healthcare is important for tracking risk for genetic conditions like Cystic Fibrosis, Down Syndrome, and Sickle Cell Anemia. I feel it is just as important for tracking risk of conditions like high blood pressure, Alzheimer's, and diabetes."

- Strongly Disagree (1)
 - Disagree (2)
 - Somewhat Disagree (3)
 - Neither Agree nor Disagree (4)
 - Somewhat Agree (5)
 - Agree (6)
 - Strongly Agree (7)
-

29 Have you ever felt that your needs have **not** been met in genetics healthcare?

- Yes (1)
 - No (2)
 - Unsure (3)
-

30 What do you feel is the biggest challenge in getting your genetics healthcare needs met?

_____ *Open Response Answer* _____

31 This information will be incredibly helpful in determining what approaches will be best for the future of healthcare in this field. We hope to not only use this data to help improve the options in genetics healthcare, but would like to pair it with other types of data outside of this survey.

Would you be interested in a follow-up to this survey as an interview?

Yes (1)

No (2)

Skip To: 33 If This information will be incredibly helpful in determining what approaches will be best for the f... = No

32 You have selected that you are interested in participating in the interview section of this study. Please copy this URL and open it in a separate window. Please be sure to still submit this survey.

https://pitt.co1.qualtrics.com/jfe/form/SV_9KtwY5Hibn2Jr3D

33 Please verify your submission.

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