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ACMG STATEMENT

Considerations for policymakers for improving health care through telegenetics: A points to consider statement of the American College of Medical Genetics and Genomics (ACMG)

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Introduction

Telegenetics, a form of telemedicine, is 2-way, interactive real-time electronic information communication between a patient and genetics health care professional(s) (ie, medical geneticists [physicians who specialize in genetics] and genetic counselors [health care workers with training in medical genetics and counseling]) as an alternate to providing health care in person at a medical office.[1,2] These services include, but are not limited to, assessment, diagnosis, consultation, test result release, education, counseling, management of care, and/or aided self-management. In general, genetics services do not require immediate physical intervention, which makes the provision of these services well suited to telemedicine. This statement is intended to assist policymakers in gaining familiarity with the current state of genetics services provided via telehealth.

Medical genetics health care professionals have been using telegenetics for more than 25 years with demonstrated success in genetics consultations and increased patient satisfaction.[3-10] Now, because of the COVID-19 pandemic, telegenetics has expanded as a necessary, effective, and invaluable care modality that allows for provision and continuation of care without the patient and genetics health care professional being in the same physical location. Most

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patients can have medical visits with their health care professionals while being in their own homes, at a clinic, or at some other site where their health care professional is not located. The increased use of telemedicine is not unique to genetics; the COVID-19 pandemic resulted in widespread adoption and use of telehealth services in nearly every medical specialty.[11-18]

There are numerous examples of how the use of telemedicine during the pandemic has enhanced patient care, including timely release and counseling of test result(s), insight into patients' home settings, behavior assessments in home environments, reduction in health care costs, and expanded care for rural and underserved populations who experience barriers to accessing health care.[19-30]

With regard to the reduction in health care costs, within the US Department of Veterans Affairs (VA) health care system, both onsite and telegenetics models are available to patients. When this shift in service delivery was enacted, service delivery also expanded telehealth services to address the limited access to genetics within the largest integrated health care delivery system in the United States.[31,32] In 2015, the VA travel reimbursement for qualified patient travel for all clinical appointments was projected to cost approximately $1 billion. In a systematic review, Russo et al[33] quantified the savings related to shifts to telehealth at a single VA hospital in White River Junction, Vermont, between 2005 and 2013, which resulted in an average travel payment savings of $18,555 per year—notably, by 2013, these savings averaged $63,804 per year. Indeed, the recent shift to additional telehealth services has and will continue to result in significant cost savings. In addition, the American Hospital Association's recent brief, "*Telehealth: helping hospitals deliver cost-effective care*," highlights the growing evidence that telehealth lowers health care costs while also improving access and quality of care.[34]

Recent shifts in service adoption, although originally due to pandemic response, have been dramatic; a survey in a large New York City hospital center reported that only 8.4% of internal medicine residents had used telemedicine within the United States before the COVID-19 pandemic, but this rate soared to 100% during the pandemic.[35] Despite the now widespread use of telehealth, barriers such as access to technology and high-speed internet, payer coverage, license restrictions, and geographic practice limitations all contribute to limiting access to telegenetics for many Americans.[36-39]

Although some of these issues must be addressed within individual health care institutions, many require federal and/or state policy action to permit the necessary changes. As such, this statement is intended to assist policymakers tasked with improving equitable access to genetics services via telehealth. The statement describes telegenetics services, the need for these services, existing barriers to technology access, actions needed to ensure equitable access, the current state of reimbursement for these services, and the effects of the COVID-19 pandemic on the implementation of these services. It also highlights patient, family, health care professional, and societal benefits; discusses areas of failure; identifies where revised federal or state policies would improve access; and makes recommendations for actions needed to ensure equitable access to efficient, high-quality, patient-centered care via telehealth/telegenetics.[40-43] In addition, it also emphasizes the need for continuation of the provision of telegenetics services after the COVID-19 public health emergency abates because it relates to refining implementation and adoption in an equitable manner. Continuation of telegenetics services has the potential to reduce disparities in access to care that exist given systemic racism, implicit bias, and many other forms of discrimination that persist within the US health care system.[8,44]

Discussion

Removal of geographic barriers and site restrictions

The COVID-19 pandemic has resulted in significant changes in the delivery of medical services through telemedicine, not limited to telegenetics, particularly related to those for which medical professionals can provide services. States generally have laws that require health care professionals providing services via telehealth to be licensed providers in the state where the patient is located. However, owing to the pandemic, regional and state agreements allowing for recognition of medical licenses from other states have been established, and some states have modified policies for telehealth to allow out-of-state physicians to enter into patient–provider relationships to help address the public health emergency. This reciprocity, which aims to mitigate inequity in the availability of the health care workforce, particularly in underserved areas, is only a single step. More work is needed to reduce the substantial barriers that prevent access to telemedicine for the patients who need it the most and to extend the reciprocity during times with no public health emergency.[44-46]

In addition, given the well-documented shortage of the medical genetics workforce in the United States (and globally), telegenetics can expand the impact of the limited number of genetic service providers.[47-56] In 2020, the US Government Accountability Office (US GAO) released the report "Genetic services: information on genetic counselor and medical geneticist workforces," which illustrated that the availability of genetics health care professionals varies dramatically between states and regions. GAO reported genetics providers are mostly located in urban centers, resulting in barriers to access for individuals who live in rural areas for a variety of reasons, including, but not limited to, the cost of travel.[57-61] For example, the state of Wyoming has no medical geneticists and has 0.86 genetic counselors per 500,000 people compared with the District of Columbia that has 19.1 medical geneticists and 18.4 genetic counselors per 500,000 people.[30,56] Without telegenetics, residents of the most underserved states or localities simply do not have access to genetic services.

In addition, barriers are created by insurer/payer policies that include certain geographic restrictions such as those that prevent coverage of telegenetics services for patients who live near health care specialists. Even families who live in urban centers with a nearby health care provider can still have travel barriers to accessing genetics services, including lack of transportation, child or elder care for other family members, difficulty traveling due to mobility or other health issues, etc. The Centers for Medicare and Medicaid Services recognized that Medicare and Medicaid beneficiaries can be hampered by such geographic site restrictions and used its authority to waive these restrictions during the COVID-19 pandemic. However, the Centers for Medicare and Medicaid Services lacks the authority to make this change permanent, and legislation is needed to change the Social Security Act for this to continue after the public health emergency has ended. This is a subject of interest among many state and federal policymakers, and the American College of Medical Genetics and Genomics has been actively engaged in these efforts.

Geographic access barriers can be especially challenging for patients with ultrarare genetic conditions for which there may be only 1 or 2 clinical specialty sites across the country (or even the world) that have the appropriate skills and experience to provide personalized care for these patients.[62-64] Without telegenetics, these patients are burdened by requirements of traveling for face-to-face interactions that often occur multiple times per year.[1,20,65,66] For example, patients with Batten disease, a rare inherited neurodegenerative and fatal genetic condition, face multiple barriers to accessing expert clinical care, but the recent incorporation of telehealth services at the Batten Disease Center of Excellence at Nationwide Children's Hospital has improved provider-to-provider communication and multisite collaboration to enhance care without the need for extensive travel.[67] Affecting families from both rural and urban areas, the burden of travel is compounded by the added costs of travel, extensive time needed away from work or care for family members, and other unique requirements, such as requiring an ill or technology-dependent patient to travel via public transportation, that may make the appointments inaccessible for some.[33]

There are more than 7000 rare diseases that affect an estimated 25 to 30 million Americans, and telehealth provides a platform to conveniently reach these patients.[68] Telegenetics allows these patients and their families to receive services from the comfort of their home or a nearby clinic, thereby improving equitable access to care. The use of telemedicine to provide genetics services has significantly increased access to health care for patients and families with rare disorders both nationally and internationally.[1,69-73]

Points to consider

- States should pursue licensure compacts and reciprocity agreements to allow greater flexibility for patients to continue to see their specialists regardless of which state they are located in.
- Geographic and originating site restrictions create unnecessary barriers that contribute to inequities in access to genetic services. State and federal policies should address as many geographic barriers as possible to reduce disparities and ensure equitable health care professional access for all patients.
- Telegenetics services should be covered for all patients regardless of proximity to a hospital, clinic, or genetics health care professional.

Technological and other barriers

Additional aspects in the provision of fair and equitable telegenetics services include both the availability of health care professionals for telemedicine appointments and the accessibility to and uptake by patients and their families. These services are often tailored to the communities served, and the lack of uniformity of access across the United States is often due to a lack of access to necessary technologies.

Telegenetics services have the potential to reduce health care disparities by increasing access to specialty clinical genetics health care professionals. The benefits of telegenetics can be fully realized when all patients have equitable access to genetics health care professionals and genomic testing. The widespread adoption of smartphones has led to a decrease in the digital divide;[74,75] however, technology issues remain a barrier for some populations. For example, the elderly may be more likely to have only a landline, which makes video appointments unavailable to them.[76] Similarly, lower income families may have less consistent access to smart devices or computers in their homes and may have limited wireless data packages.[75,77,78] This means that they can only benefit from telegenetics services that can be appropriately delivered as an audio-only visit. Policies are needed to improve access to such technologies either within the home or at community centers that allow for appropriate privacy.

With respect to genetics services, another study in New York City demonstrated the persistence of technological barriers in that nearly one-third of patients did not have the technological capacity to engage with genetic counseling providers, even when the COVID-19 pandemic moved approximately 40% of all patient interactions to communication via telegenetics.[24] These experiences highlight the need to prepare not only health care professionals but also patients for these services to ensure that the benefits of telegenetics are accessible for all.[79,80] There is a clear need to ensure that underserved populations have access to technological resources to benefit equitably from the availability of telegenetics.

Even if patients have access to computers or other smart devices, reliable internet access is often still necessary to support a telegenetics visit. Many communities in the United States, especially those in rural areas, do not have reliable broadband high-speed internet, which limits their ability to access telegenetics services that require video capabilities. Although the SafeLink Wireless program, or the federal Lifeline program, which provides discounted phone services for 13.3 million low-income subscribers, aims to "*ensure all Americans, including low-income consumers and those who live in rural, insular, high cost areas, shall have affordable service and [to] help to connect eligible schools, libraries, and rural health care providers to the global telecommunications network*," and these services have not been updated to the modern era to include high-speed internet access.[81,82] This program, with roots in the Telecommunications Act of 1934 and updated by the 1996 Telecommunications Act, provides a precedent for further action by Congress to ensure access to necessary telecommunication services for all Americans. Promising federal support was announced in January 2021 by the US Department of Health and Human Services, including an $8 million investment to address gaps in rural telehealth, intended to serve as the basis for continued support for the expansion of telehealth services across the country.[83] The Infrastructure Investment and Jobs Act passed in November 2021 contains $65 billion for broadband internet and will be a monumental step in addressing this digital divide and improving access to clinical genetics care.[84] Many states are also considering legislation that would improve broadband access to rural communities.

Although not specific to telemedicine alone, another challenge for ensuring equitable access to telegenetics is language and communication barriers. Currently, there are widespread differences in the ability of clinical genetics health care professionals to offer access to medical interpretation services for patients with hearing or visual impairments, communication disorders, and non-English speaking patients. Software used to support clinical services must ensure accessibility for those with barriers to direct verbal communication. Examples of such software capabilities include appropriate screen readers for patients with vision impairments, translation services, and closed captioning and/or American Sign Language interpreters. Without these services, patients may not effectively engage with health care providers nor are they able to retrieve additional resources regarding their condition.[85] Provision of interpreter and other specialized communication services may be limited by payer coverage and reimbursement policies. Larger health institutions may be better equipped to provide these services; however, it is critical that all health care professionals and patients have access to appropriate services that allow for communication of genomic information and provision of services to patients.

Points to consider

- Patients' access to high-speed internet, either through ownership or through public services (eg, local library, public health service), continues to limit the widespread deployment of telegenetics services. Policies are needed to ensure access to reliable high-speed internet such as through the availability of free and low-cost high-speed internet plans.
- Policies are needed to improve patient access to computers or other appropriate smart devices (eg, smart phone or tablet) within their homes or at nearby community facilities, including appropriate technology support to ensure patients can successfully use the technology.
- Policies are needed to ensure that all clinics are able to provide appropriate interpretation services for those with either limited English proficiency or visual, hearing, or communication impairments.
- Payers and governmental entities should develop and implement quality measures for virtual genetic services to help health care professionals address communication barriers and improve equitable access to the best virtual genetic services.

Coverage and payment parity

Coverage and payment parity for services are critical for ensuring equitable access for all clinical genetics patients. Coverage parity refers to payer coverage of all health care services for all beneficiaries regardless of the service delivery method (ie, in-person vs telegenetics). Payment parity refers to reimbursing identical services at the same rate regardless of whether they were provided in-person or via telehealth. Regardless of the platform used, these services should be reimbursed similar to in-person clinic services.

Although not all health care services can be provided via telemedicine, eg, those that require a hands-on physical examination or medical procedures, most telegenetics visits have been shown to be effective and provide similar care to that of in-person genetics visits. Many appointments with a genetics health care professional are primarily centered around discussion and counseling, a type of visit that lends itself well to being conducted via telehealth.

For a telegenetics visit, the communication and information exchanged between a health care professional and a patient should be equivalent to that of a traditional face-to-face appointment. This is critical to maintain quality of care. Because each patient visit is unique, the genetics provider must determine whether telegenetics or an in-person visit is most appropriate for each appointment, eg, an in-person physical exam using specific equipment to provide a diagnosis vs a visit focused on discussing the results of genetic testing. This applies to both new and established patients, and policies should give health care professionals appropriate flexibility. In some cases, telehealth may offer additional benefits by allowing health care professionals to interact with patients in their home environments. This can elicit information not readily available in the clinic, including, but not limited to (1) reduced patient and family anxiety, which may facilitate more open dialogue regarding the complex medical needs of the patient, (2) brief introduction to other family members, and (3) observation of patient interactions in the environment, which may identify support needs (ie, physical, occupational, and/or speech therapy, psychology, and social work and/or services).[58]

During the COVID-19 pandemic, Medicare coverage extended telehealth services for both new and established patients at the same reimbursement rate as in-person visits. However, there has been hesitancy about making these policies permanent for new patients. In a 2021 Medicare Payment Advisory Commission report, the committee cited recent examples of fraudulent schemes and suggested that a face-to-face visit should be required before a provider can order certain tests, such as genetic tests, as a means for reducing the potential for fraudulent schemes to become more common in the future.[86] Although reducing the potential for fraud is important, the solution should not lead to reduced access to services or to a solution that punishes the patients or exacerbates disparities. Requiring certain patients, on the basis of medical insurance, to attend an in-person visit without a perceived need for a face-to-face encounter by both provider and patient is an unnecessary burden that creates inequity in access to care.

There are several types of communication platforms for telegenetics services, including audio-only (telephone required), audiovisual (computer, tablet, or mobile device, as well as high-speed internet access required), and other platforms. Not all telegenetics services are appropriate via telephone only nor do all telegenetics visits require both video and audio to effectively communicate. A new patient visit may require both video and audio capabilities to provide a comprehensive evaluation of patient health and status, but a follow-up appointment for the coordination of testing may only require a phone conversation. It is the responsibility of the health care provider to choose the most appropriate modality after considering the care being delivered and patient preferences. However, some of these communication methods are not billable to many payers.

The lack of uniform insurance coverage and reimbursement for telegenetics services continues to create barriers to equitable access by limiting patients' appointment options. There are differences in coverage parity based on the health care professional(s) engaged in the telegenetics service, the platform(s) used to communicate, and the type(s) of information communicated during the appointment. For example, many states' Medicaid programs do not comprehensively cover telemedicine services, leading to an inequity of care between those with public and those with private insurance.[39,74,87] Although Medicare may cover certain types of telehealth visits, the Social Security Act currently does not permit coverage of audio-only visits. As a result, patients who do not have access to high-speed internet or broadband coverage and only have a landline telephone can only access these services if they are able to pay out-of-pocket.

To be appropriate for any type of telehealth, the quality of care delivered by telehealth must be equivalent to that delivered during an in-person encounter, which further supports equivalent reimbursement. Of course, there are additional indirect factors that must be considered when determining reimbursement rates.[88-90] For example, although an in-person visit requires more overhead resources, such as use of an examination room and staff to check in the patient, telehealth visits require specialized communication equipment, provider training, and tech support for both the provider and patient.

Although most states require private payers to cover telehealth services (coverage parity), payment parity laws are much less common.[87,91] For example, there are often differences in reimbursement between traditional face-to-face visits and telegenetics visits even when the same level of care has been provided (eg, explaining clinical test results to families in an office or via telegenetics). If these differences in reimbursement persist, this could decrease the use of telemedicine even when it is the most accessible modality for the patients served by the health care professional(s). State legislators must take action to continue to pass legislation that improves both coverage and payment parity of telehealth services to ensure that more Americans are able to access genetic services.[92] Federal policies also must ensure that coverage and payment parity for telehealth services exists for public payers. Coverage and payment parity are not only necessary for patient access but also are crucial for ensuring that health care professionals and institutions are financially able to continue to provide telehealth services.

Points to consider

- Policies for uniform coverage of telegenetics services for all patients are needed to reduce inequities in access. This applies to both new and established patients regardless of the platform determined to be most appropriate for the visit.
- Coverage parity is necessary to ensure that health care professionals and clinics can continue to offer telegenetics services to patients.
- Payment policies should consider quality of care, technology services, and ancillary costs to ensure that services are reimbursed appropriately and equitably regardless of the delivery modality (in-person vs telemedicine).
- Policies designed to reduce the potential for fraud should not limit patient access to genetic testing services, including those delivered via telehealth.

Summary

Although the COVID-19 pandemic has expedited the integration of telemedicine into genetic services, only a concerted effort will ensure that all Americans can benefit from these services. The point discussed in this statement should be viewed as considerations for federal, state, and institutional policymakers, including payers, tasked with ensuring equitable access to telemedicine, including telegenetics, even after the COVID-19 public health emergency has expired (see Table 1 for resources). Improved telehealth policies are necessary to enhance patient care and reduce disparities in access to genetics health care to patients throughout the United States.

Table 1 Resources for the telegenetics/telemedicine/telehealth policy

Resource	Brief Outline
The Center for Telehealth and e-Law (CTeL)	• A legal and regulatory telehealth research institute • Supports sustainable organizational models focused on harmonizing regulatory and legal boundaries to result in the highest quality health care
Center for Connected Health Policy (The National Telehealth Policy Resource Center)	• A nonprofit, nonpartisan organization focused on advancing state and national telehealth policies to promote better systems of care, improved health outcomes, and enhanced health equity of access to quality, affordable health care • Supports the integration of telehealth virtual technologies into health care systems
National Conference of State Legislatures	• A bipartisan organization providing states support, ideas, and information • Supports activities of legislatures to facilitate the exchange of information
National Consortium of Telehealth Resource Centers (NCTRC)	• Aims to bring sustainable telehealth programs to improve outcomes for rural and underserved communities • Supports activities of the 12 regional and 2 national Telehealth Resource Centers (TRCs), which aid organizations to overcome barriers to the implementation of telehealth services
National Coordinating Center (NCC) for the Regional Genetics Networks (RGNs)	• Aims to bring genetic services, including telegenetics, closer to local communities • Provides a telegenetics resources repository, including resources specific to each region of the US • Supports activities of the 7 Regional Genetics Networks (RGNs), each of which may provide additional telehealth resources that are unique to their region

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Conflict of Interest

H.E.W. serves as a director in a clinical laboratory that performs a breadth of genetic and genomic analyses on a fee for service basis and is an employee of Tempus Labs, Inc and has equity ownership in the form of incentive stock options and restricted stock units. L.A.'s contributions to this document were accomplished in her personal capacity. The views expressed do not necessarily reflect the official views of, nor an endorsement by, the State of Hawai'i Department of Health, the Health Resources & Services Administration, the Department of Health and Human Services, or the United States Government. M.B.D. is employed by eviCore, a testing utilization company. D.F. is a consultant to CareSource, a managed care Medicaid payer. D.V. is a consultant for AstraZeneca, Sanofi, and SpringWorks, as well as the principal investigator for Takeda, Ultragenyx, Levo Therapeutics, and Soleno Therapeutics clinical trials. All other authors declare no conflicts of interest.

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