

Title: Impediments and Solutions to Telegenetics Practice: Meeting Report

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Authorship: Nirav N. Shah, MD, JD¹, Lynn D. Fleisher, PhD, JD¹, Hans H. Andersson, MD², Becky B. Butler, MSSW, LCSW³, Barry H. Thompson, MD⁴, Judith Benkendorf, MS, CGC⁴, Alisha Keehn, MPA⁴, David Flannery MD⁵, Dale C. Alverson, MD⁶, Sylvia Au MS,CGC⁷, Lisa Robin⁸, James Puente⁸, Joey Ridenour, RN, MN⁹, and Michael S. Watson, MS, PhD⁴

¹Sidley Austin, LLP, Chicago, Illinois; ²Tulane University School of Medicine, New Orleans, Louisiana; ³University of Arkansas for Medical Sciences, Little Rock, Arkansas; ⁴American College of Medical Genetics, Bethesda, Maryland; ⁵Medical College of Georgia, Augusta, Georgia; ⁶University of New Mexico School of Medicine, Albuquerque, New Mexico; ⁷Hawai'i Department of Health, Honolulu, Hawai'i; ⁸Federation of State Medical Boards, Washington, DC; ⁹Nurse Licensure Compact Administrators, Chicago, IL

Corresponding Author:

Michael S. Watson, MS, PhD
American College of Medical Genetics & Genomics
7220 Wisconsin Ave.
Suite 300
Bethesda, MD 20814
301-718-9603 tel
301-718-9604 fax
mwatson@acmg.net

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ABSTRACT

Medical genetics is a prime example of a specialty to which many patients have insufficient access. Telemedicine has the potential to deliver health care to individuals and families in medically underserved areas to connect patients and providers across geographic distances. On November 5th and 6th, 2009, a working group, convened by the American College of Medical Genetics & Genomics (ACMG) and the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (NCC), met to discuss the challenges facing wider adoption of telemedicine for the provision of clinical genetics services. Broadly called telegenetics, this evolving mode of medical service delivery can be used for the assessment, diagnosis, management, treatment, education, and counseling of patients and families dealing with a wide array of genetics issues. This paper summarizes the working group meeting and the resulting recommendations including adoption of multistate licensing, national credentialing, appropriate financing and reimbursement, and continued investment in technological development to increase usability and national infrastructure.

Key Words: telemedicine, telegenetics, telehealth, medical licensure, financing, reimbursement, telemedicine infrastructure

INTRODUCTION

The American Medical Association defines telemedicine as the “delivery of health care services via electronic means from a health care provider in one location to a patient in another.” Telemedicine makes use of a constellation of emerging information communication technologies to connect patients and providers across geographic distances. If properly utilized, telemedicine has the potential to deliver health care to individuals and families in medically underserved areas where patient demand exceeds provider capacity, especially in medical specialties. Medical genetics is a prime example of a specialty to which many patients have insufficient access. In 2009, there were approximately 1,200 clinical physician geneticists in active clinical practice in the United States, comprising only 0.19 percent of the 700,000 physicians in the US. Clinical geneticists (defined as those physicians who are certified in the Clinical Genetics specialty by the American Board of Medical Genetics) spend roughly 45 percent of their time involved with direct patient care¹. They are heavily concentrated in urban areas and are often connected with major academic institutions. The maldistribution and limited number of genetics practitioners means that medical genetics services are often unavailable to individuals living in rural, or even mid-sized towns. Moreover, as research into genetic disorders continues and our ability to manage genetic diseases expands, the need for additional medical geneticists will surely grow. Experts estimate that one medical geneticist is needed for every 250,000 individuals—a ratio that the U.S. is currently unable to achieve. Nor is it likely that this optimal ratio will be attainable in the future unless there is a significant expansion of training capacity or other means to ensure increased numbers of genetics specialists.

In 2007, the NCC Telegenetics Workgroup conducted a national survey of genetics professionals in order to understand how telecommunications technologies were being utilized in genetics care and education. The web-based survey was offered to members of the ACMG (approximately 1350) and the National Society of Genetic Counselors (NSGC) (approximately 1800); of the 434 respondents, 34 percent were genetic counselors, 29 percent were physicians,

and 13 percent PhD geneticists. Respondents indicated that most telegenetics activities occurred in academic health care/university hospitals (51%) and state health departments (9%). Forty-three (43) percent responded that they had used or were using telegenetics “to provide clinical services, to teach or to learn.” The clinical uses of telegenetics were to provide genetic counseling (67%), follow-up evaluations (52%), initial clinical evaluations (45%), and teaching (45%). Of the 57 percent who responded they never used telegenetics, 79 percent indicated they perceived telegenetics as a useful activity, but only 16 percent had plans to develop telegenetics. The barriers most frequently identified by non-users were: unavailability of technology (54%); high cost (22%); and institutional barriers (20%). Some telegenetics users provided services that crossed state lines (45%) and even national boundaries (17%).

Funding for most telegenetics programs (53%) was dependent upon grants: federal (52%), state (38%), private (23%) or institutional (20%). While 65 percent used telegenetics for providing clinical services, only 34 percent of those programs were supported by clinical billing/fee for service. While reimbursement for telegenetics services appears to be as adequate as that for face-to-face encounters^{2,3} most programs have not demonstrated the ability to sustain these services without the use of grant funding to support setup costs and the additional personnel needed.

Telemedicine offers an opportunity to close this gap in the provision of genetics services. Technologies such as synchronous video conferencing, interactive imaging, and remote diagnosis allow medical genetics services to be accessible to both patients and primary care physicians who are located at a distance from genetic service providers. Yet, despite the promise of telegenetics, many barriers remain. Licensing and credentialing pose challenges to providing telegenetics services across state lines. While patient demand for telegenetics services is strong, financing partnerships between geneticists and primary care practitioners remains difficult. Even where financing is available, obtaining reimbursement for the providers of genetic services can be problematic because of varying regulations in different states. The technology itself can be a barrier for busy primary care practices whose facilities may not be amenable to teleconferencing. As a result, while telemedicine technology has advanced considerably in recent years, its adoption remains slow and costly. Although patient satisfaction with telegenetics encounters is high, a preference for “face-to-face” interactions among some patients may impede the field’s future growth.

This white paper discusses these four major areas of challenge—licensure, credentialing, financing and reimbursement, and technology and delivery of telegenetics services—and analyzes how each, if unaddressed, will continue to pose impediments to the broader utilization of telegenetics. At the end of each discussion there are recommendations from the working group regarding those legal, institutional, and financial best practices that can be adopted to ensure that genetics services are more widely available to all individuals, regardless of their location.

I. Licensure

1. *Background*

According to the American Medical Association, telemedicine has “crystallized the tension between the states’ role in protecting patients from incompetent physicians and protecting in-state physicians from out-of-state competition, and the desirability of ensuring patients’ access to the highest quality medical advice and treatment possible, wherever located.”⁴ It comes as no surprise, then, that licensure stands as one of the primary barriers to more widespread provision of telegenetics services.

Historically, regulation of the practice of medicine is a power granted to states by the 10th Amendment to the Constitution. Thus, in the United States, providers are licensed by state rather than nationally and must apply to each state separately for such licensure. All states require that any physician who provides medical care for a patient holds a valid license in the state in which the patient is located. With the broad expansion of telemedicine, this means physicians who practice across state lines need multiple state licenses. Obtaining licenses in multiple jurisdictions — each of which may have onerous application and varying yearly reporting and education requirements — is a hurdle that many providers simply are not willing to face. For individuals living in the several states with no medical geneticists, the inability of physicians to provide telegenetics consults often means that patients must travel to nearby states for consultative medical care, at great time and expense, or forego necessary medical treatment.

Licensure Portability Development

According to the Office for the Advancement of Telehealth (OAT), a division of the Health Resources and Services Administration, there is a need to stimulate cooperation among licensing groups to discuss issues of licensure portability. Toward that end, OAT has been issuing grants to state medical licensing boards to encourage states to adopt policies that would lead to increased access to providers, particularly in underserved areas. Starting in 2004, OAT began making grants to foster multistate telemedicine projects. Continuing through 2006, OAT authorized funds to promote the reduction of barriers to telemedicine— both in terms of access and provision of such services.

At the state level, licensure boards have been encouraged by the Federation of State Medical Boards (FSMB) to reduce redundancies in the application and credential verification processes. At present, 14 state medical boards are involved with this initiative. The American Recovery and Reinvestment Act of 2009, more popularly known as the stimulus package, included \$1.5 million of funding for such programs.

Although most states recognize the intrastate practice of telemedicine, none currently allow(s) physicians from outside states to provide services to patients within the state without being duly licensed in that state.^{5,6} Thus, physicians wishing to offer broad telemedicine or telegenetics services must navigate the present patchwork of multiple state license boards, along with various territorial and tribal licenses. The time and expense required for these applications and renewals, along with the variety of requirements related to medical record retention, informed consent, and confidentiality, means that most physicians provide telemedical services only within their own state. Providers that do offer telemedicine or telegenetics services without proper licensure from the state in which the patient is located risk civil and criminal sanctions for practicing medicine without a license.

Most states recognize a limited exception to the licensure requirement for out-of-state physicians

Multi-State Licensure Compacts

The National Council of State Boards of Nursing advocates a “licensure compact” model to cure some of the hurdles facing telemedicine providers. This model is already in place in the nursing profession and has contributed to the ability of nurses to travel and practice in a variety of states without being individually licensed in each state. The nursing compact aims “to simplify governmental processes, remove regulatory barriers, and to increase access to safe nursing.” At present, there are 24 states in the licensure compact. Much like a driver’s license, member states agree to grant mutual recognition to a nursing license properly issued in a nurse’s primary state. In effect, the nurse has one license in his or her home state, but can practice on a privilege basis in any other state that is a member of the compact. The nurse is subject to the Nurse Practice Act of the state in which he or she is practicing.

At a broad level, interstate compacts are agreements that carry the same force of statutory law between the several states that have adopted them. They are engineered to provide a coordinated remedy for problems facing multiple states. Member states retain their own sovereignty, but are encouraged to cooperate and share information with each other with respect to solving these problems. Compacts are not uncommon, and the average state is a member of approximately 25 compacts—the most well-known of which is the Driver’s License Compact.

Many believe that the nursing compact model could provide a roadmap for telemedicine licensure. Like the nursing compact, a “telemedicine compact” would allow providers to offer telemedical services in member states. The provider’s primary state of residence would still be the main state of license, but enforcement actions could be brought against the provider in any state in which he or she practices. While such a compact could provide a solution to the problem of interstate licensure, passage of a telemedicine compact could take some time and may face opposition from medical licensure boards, which may not want to cede their individual sovereignty.

providing in-state “consultations.” For example, an in-state physician may ask an out-of-state specialist to review slides or X-rays on a per patient basis under this consultation exception. But for telegenetics, where the geneticist “meets” with the patient, and offers advice and guidance not to the referring primary care physician, but directly to the patient, the “consultation” exception is unlikely to apply.^{5,6} Moreover, many states have moved to limit the ability of a telemedicine provider to practice across state lines through their strict licensing requirements. In doing so, these states have restricted the access to medical genetics

consultations for many patients, in particular, those unable to travel to major academic centers for a medical genetics consultation.

To date, at least 32 states have adopted licensure regulations relating to the practice of telemedicine. Most of those regulations require full in-state licensure for out-of-state telemedicine providers.⁷ The Illinois statute defines “telemedicine” to include “rendering written or oral opinions concerning diagnosis or treatment of a patient in Illinois by a person located

outside the State of Illinois as a result of transmission of individual patient data by telephonic, electronic, or other means of communication within this state.” The Act prohibits the practice of telemedicine without a license, but does provide exceptions for “periodic” consultations, second opinions, and follow-up medical care.

In Illinois, for example, the Medical Practice Act provides that an out-of-state physician treating a patient in Illinois via telemedicine submits herself or himself to the jurisdiction of the courts of Illinois and could face criminal penalties for the unlicensed practice of telemedicine. Thus, an out-of-state medical geneticist providing regular interpretations of tests from patients located in Illinois must be fully licensed in Illinois or risk serious consequences. These restrictions unmistakably threaten the expansion of interstate, national, and international cooperation in the field of telemedicine/telegenetics. They imperil the long-standing pattern of specialty diagnostic and interpretive services that have been provided across state lines without regard to licensure and ultimately threaten the health of patients, who may lose the right to see a geneticist or other provider of their choice.

State licensure boards respond to these concerns by claiming that out-of-state physicians practicing telemedicine on in-state patients may not be as qualified as in-state physicians and thus need to be subject to the licensing and standard of care guidelines of that state. Many contend, however, that such restrictive measures are there for the benefit of already-licensed in-state physicians and that state boards are more interested in protecting those physicians than patients.⁸

2. Alternative Licensure Proposals

As early as the 1990s, various groups proposed models to streamline the process of licensing physicians in order to encourage the growth of telemedicine. The Federation of State Medical Boards (FSMB) developed a model act that included provisions for a “special telemedicine license.”⁹ In 1996, HRSA sought public comment and “suggestions for easing licensure barriers to physicians and other health care professionals providing telemedicine services across state lines.”¹⁰ Congress has introduced a variety of telemedicine-related measures, although none have passed. In 2004, Senator John Edwards introduced the “Telehealth Improvement Act of 2004” which called for greater promotion of telemedicine and interstate licensure; the measure was not adopted.¹¹

In his testimony accompanying the presentation of the *Telemedicine Report to Congress* in 1997, Commerce Secretary Michael Kantor observed that a key barrier to more widespread provision of telemedicine is “the licensure of telemedicine professionals who work across state lines or who provide services on a multi-state basis.”¹² The 1997 *Telemedicine Report to Congress* identified several alternatives to full, in-state licensure. See Table 1.¹³

Table 1: Telemedicine Licensure Options

Proposal	Strengths	Weaknesses
Separate licensure in each state (status quo)	Allows full vetting and monitoring of applicants	Administratively burdensome and impedes growth of telemedicine practice
Limited telemedicine license, <i>e.g.</i> , FSMB Model Act	Allows enforcement and oversight; retains state sovereignty	Still requires physicians to complete limited application and maintain licensure in each state; patients may still need an in-state primary care provider to assist with medical care.
Licensure based on negotiated reciprocity	Very little administrative burden on physicians who wish to practice telemedicine	Administratively burdensome at the state level; states that enter into reciprocity agreements may not match true needs of patients for telemedicine services
Nursing interstate compact	Easy for states to adopt a compact, thereby increasing likelihood that individual states will join; enforcement actions retained in state of primary residence	Disputes between states may be difficult to adjudicate; drafting a mutually acceptable compact may be difficult
Registration	Easy for physicians who wish to practice in another jurisdiction to register with state medical board	May not allow sufficient vetting and oversight of physicians
Multistate/National licensure	Would eliminate all administrative licensing burdens associated with telemedicine	May encroach upon a power traditionally reserved for states

3. Recommendations

As the American Bar Association (ABA) has observed, “The substantial and ongoing administrative, financial and legal burdens imposed by requirements for multiple licenses for telemedicine practice outweigh any potential arguments in their favor. If the *true* goal is to allow each state’s residents to have access to the best medical care in the country, both within and outside of that state, all states must act to reduce barriers to interstate telemedical practice, not erect new ones.”¹⁴

The working group agrees with the resolution adopted by the ABA in 2009, which recommends adoption of a multistate licensure model featuring a mutually recognized telemedicine license. Under this system, a physician would file a single application and indicate for which states he or she would like such a telemedicine license. The telemedicine license would entitle the physician to practice remotely in the jurisdictions in which he or she obtains licensure. Any currently practicing physician with a valid and unencumbered license would be eligible to apply. As part of the process, each state would agree to harmonize its own requirements for licensure, to the extent that such requirements differ today. The physician would agree to comply with the fee schedules, regulations, and educational requirements of each state that he or she has selected. (Ideally, those requirements could also be harmonized, greatly streamlining the licensure compliance process.) The physician would also agree to submit to personal jurisdiction in each state in which he or she practices. In concert with this effort, states would also adopt a uniform definition of telemedicine and telemedical practice.

Federation of State Medical Boards

The FSMB believes that license portability may encourage greater numbers of providers to offer telemedicine services. License portability is a system of licensure whereby providers can practice in states that recognize the physician’s license and credentials. The individual state’s jurisdiction is not limited in any way, but the process of obtaining such a license is facilitated. Portability would offer numerous benefits to geneticists wishing to provide services and counseling to patients in different states.

At the heart of a license portability model is the notion of centralized application and processing. Ideally, providers would submit their licensure applications online using a uniform application. This application would go first to a central clearinghouse that would verify the applicant’s credentials and forward the application to the relevant states. However, variations on the model exist, including an expedited process whereby physicians in good standing in one state could obtain licensure in another state without submitting a new application.

States, too, have incentives for participating in the uniform application process. There already is one primary form that states can use to streamline the credential verification process, which saves time and money. Applicants can use the Federal Credential Verification Service (FCVS) to enter their information and pre-populate subsequent license applications to states. At present, 70 percent of data that state license boards receive has already been pre-populated by FCVS. The uniform application also includes reports from the FSMB on each applicant.

II. Credentialing

1. *Background*

Credentialing refers to a procedure for determining whether an individual practitioner is qualified to provide certain services. With respect to telegenetics, questions arise as to whether a provider needs to be credentialed at the institution *from* which the telemedicine physician's services are being requested or at that physician's home institution—or both.

Privileging involves a delineation of what clinical services a particular provider is authorized to offer to patients within an institution. Since medical geneticists often situate their practices within a hospital or other similar healthcare facility, the geneticist is required to be

Telemedicine/Telegenetics: The Military Experience

The military has been involved with the successful development and implementation of telemedicine systems for over a decade. Initial assessment of telemedicine as a venue for distant clinical and diagnostic evaluation of patients with suspected genetic disorders was undertaken in 1999-2000 with demonstrable success. The U.S. Army Telemedicine and Advanced Technology Resource Center (TATRC) coordinated the linkage of clinical geneticists at Walter Reed Army Medical Center, Washington, DC, the National Naval Medical Center, Bethesda, MD, and the USAF Medical Genetics Center, Keesler AFB, MS. The goals were to show the capacity for appropriate initial assessment of the patient and the potential to avoid unnecessary patient/family travel.

The military currently has medical geneticists assigned to seven locations in the United States. These specialists and their nursing and genetic counselor colleagues provide on-site and distant consultation for patients and physicians throughout the United States and at military facilities abroad. Given the expansion, increased sophistication, and more effective utilization of telemedicine networks, telegenetics services should be further evaluated in order to address better the needs of patients and the providers who care for them, regardless of location.

Credentialing and privileging of providers of telemedicine services remain as challenges to the practice of medicine. State jurisdictions impact military providers to a lesser degree than their civilian counterparts, and the manner of granting telemedicine privileges to military practitioners may provide a useful model for non-military institutions to consider.

credentialed and privileged at that institution. The process can be heavily regulated by governing bodies, including the Centers for Medicare and Medicaid Services (CMS) and The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO, hereafter referred to as The Joint Commission), as well as by various state laws, and the outcome can determine a provider's ability to practice.

Some institutions, such as the U.S. Air Force, have credentialed and granted privileges for decades to medical geneticists specifically, separate from the more traditional specialties such as pediatrics, obstetrics, and internal medicine. Such privileging is appropriate in clinical practice and would seem applicable also to providers of telegenetics consultations.

Telemedicine and telegenetics pose new challenges for the credentialing and privileging processes. While the telegeneticist will likely need to be credentialed at his or her originating institution, remote sites may also want to credential the provider for insurance or legal reasons. Yet the relative scarcity of medical geneticists means that many originating sites may not have the institutional knowledge to properly evaluate, credential and privilege geneticists. Finally, geneticists, who already see large numbers of patients and families and are trying to ease patient wait times

through the use of telegenetics, do not have the time to complete licensure and credentialing applications to multiple states and hospitals.

One of the Medical Staff Standards of The Joint Commission has required sites receiving telemedicine services (also known as “originating sites”) to credential and privilege physicians, including radiologists, pathologists, and, presumably, medical geneticists. In 2004, The Joint Commission revised this Standard in an attempt to reduce the burden on originating sites, many of which are small rural hospitals. The new Standard applies to Licensed Independent Practitioners (LIPs) at originating sites where the practitioner provides professional services, has total or shared responsibility for the patient’s care, and provides services via telemedicine. In those instances, practitioners at the distant site may be credentialed at the originating site in one of three ways:

1. Traditional credentialing and privileging may be done at the originating site, following M.S. 4.10-4.110.
2. The practitioner may be credentialed and privileged at the originating site using information from the distant site, if the distant site is Joint Commission accredited.
3. The originating site may rely entirely on the credentialing and privileging of the distant site.

2. Recommendations

The working group recommends that credentialing for telegenetics providers be done at a national level. Geneticists should be required to submit a uniform credentialing application to a central organization, which possesses the skills and institutional knowledge to properly evaluate and credential genetics providers. Such a national credentialing system could eliminate disparities in credentialing from institution to institution and could also help foster a broader movement toward national credentialing for all medical professionals. A national credentialing system could rely on the Federal Credentialing and Verification System (FCVS) developed by the Federation of State Medical Boards.

Absent a national credentialing process, the working group recommends that telegenetics providers be credentialed at originating sites by proxy. Such “proxy credentialing” relies on the due diligence and expertise of the distant site and allows the originating site to adopt that knowledge when authorizing geneticists to offer their services. Credentialing by proxy, as outlined by The Joint Commission, reduces the credentialing burden for the originating site, particularly in situations in which there may be large numbers of licensed, independent practitioners who wish to provide telemedicine services. Credentialing by proxy also reduces the administrative burdens faced by geneticists since they would not need to re-submit their credentials and undergo verification at each originating site in which they wish to establish a presence. As a result, providers might be expected to offer telegenetics services at an even greater number of locations.

Finally, the working group recommends that CMS adopt either the national credentialing or the credentialing by proxy approach outlined above.

III. Financing and Reimbursement

1. *Background*

Telemedicine and telegenetics face unique challenges with respect to financing and reimbursement. Genetics services in general are often not reimbursed at rates sufficient to sustain long-term programs. When providers change locations, medical genetics patients, who often require lifetime follow-up, suffer. This is especially true in the case of rare genetic disorders, including inborn errors of metabolism, about which few providers have expertise. Telegenetics addresses continuity of care problems by allowing patients to see providers with whom they have existing relationships regardless of location. At present, however, telegenetics programs also do not appear to be sustainable through standard billing and reimbursement. Typically these programs are supported by grants from various agencies or institutions. When the funding for the grants end, programs often disappear or move in order to secure new funding.

Reimbursement is only one piece of the puzzle. The initial financing required to establish telemedicine services can be substantial. Centers must budget for:

1. Setup costs for equipment and space;
2. Credentialing for physicians and additional staff at the originating center; and
3. Personnel costs for each side of the telegenetics event.

As with financing, cost recovery for the establishment of telegenetics services usually involves grant support either from a state or federal agency or from a regional entity, such as a hospital or clinic.¹⁵

Challenges to sustaining telegenetics include increasing the volume of clinical genetics services and remedying the paucity of clinical geneticists who can provide services through telemedicine or in-person. No significant data exist to evaluate the adequacy of reimbursement in telegenetics, but telemedicine in other areas of clinical service suggest that reimbursement by Medicaid or private payers is at or near levels for reimbursement of in-person services.¹⁶ Recent data by Smith and colleagues are instructive on this point. Smith evaluated reimbursement for the provision of telegenetics services in Maine. During a 34-month period, 39 people received a genetics consultation via telemedicine in 22 scheduled clinics. By comparison, 15 people received telegenetics services at the onsite clinics during this period and reimbursement data from these encounters was used for comparison. The mix of private and public payers was broad and included Aetna, Anthem BCBS, Maine Medicaid, Tricare, Cigna, Federal BCBS, Great West Life, HMO Maine, Medicare Complete Choice, Primecare Medicaid, and United Healthcare. The clinics submitted claims for reimbursement with the relevant CPT code and the telehealth modifier “GT” as well as the ICD-9 code V63.0. Payers paid, on average, 30 percent of the total amount for telegenetics patients as compared with 26 percent for in person encounters.¹⁷

Even if reasonable reimbursement for telegenetics can be obtained, insufficient demand may continue to make telegenetics sustainability dependent upon grant funding or contracts. All current telegenetics programs are dependent upon such time-limited funding.¹⁸⁻²⁰ Indeed, in a survey of US geneticists and genetic counselors, 65 percent of telegenetics activity centered on clinical services, but only 34 percent of the telegenetics activities were supported at least in part by clinical billing.²¹ Additionally, obtaining proper reimbursement requires use of specific telemedicine modifiers, which, if not correctly coded, may result in denied payments.

Another problem that may constrain reimbursement is the specific legislative language surrounding proposals to furnish reimbursement for telemedicine services. Certain states offer reimbursement only if the service was delivered to patients in a frontier or rural setting. Such statutes present a problem for genetics services, as geneticists are under-represented in many small and large cities, as well as in “frontier” settings.

The University of New Mexico Experience

The University of New Mexico has a thriving telemedicine program that has worked to foster partnerships with various primary care outlets across the State to provide high-quality healthcare to underserved populations. Working through the University’s Center for Telehealth and Cybermedicine Research, the University has created programs that increase access to specialty care, reduce travel times and costs for patients and their families, and provide greater continuity of care. At present, there are more than 100 sites in New Mexico connected with a variety of health care provider organizations. Under the direction of Dr. Dale Alverson, the University’s work has made it possible for patients—many of whom are unable to travel because of their medical conditions—to receive top-quality healthcare in their hometowns.

While the Center itself does not provide any clinical services, it assists off-site locations with technical, operational, and business planning as they move forward with their own partnerships. In one instance, the Center has assisted in creating a module to teach primary care physicians about new Hepatitis C treatment modalities. In another module, fetal ultrasounds of high-risk pregnancies are assessed before requiring the mother to travel to a more specialized center. Alverson’s team has also pioneered a system of telemedical trauma triage, where specialists at trauma centers read radiological images of trauma victims before initiating a transfer. In 44 percent of the cases, no transfer was required. And more than 50 percent of the time, the trauma specialist recommended management changes to the on-site physicians. By fostering partnerships between providers and local sites, these programs have made high-quality healthcare available to underserved areas of New Mexico.

Finally, an often ignored benefit of telemedicine is the reduced carbon footprint. For example, the return trip from Roswell to Albuquerque, where the University of New Mexico is located, is 400 miles and can take as long as six hours. In a standard Honda Accord traveling at 70 miles per hour, this trip can be expected to generate nearly 300 pounds of carbon. Fuel and auto expenses could total \$200. By conducting the visit telemedically, these costs—both direct and indirect—are effectively reduced to zero.

Carbon calculated at: www.costtodrive.com

2. Proposals for Financing and Reimbursement

Various proposals have been put forth to encourage broader adoption of financing and reimbursement strategies designed to increase the spread of telegenetics..

Unique Needs in Telegenetics Policy

Telegenetics has unique policy needs that must be addressed

before widespread adoption can be achieved. A group in Georgia has structured clinics across the state that has conducted hundreds of patient visits. Originally called GSAMS, the system facilitated visits for a wide array of patients, most of whom required follow-up after in-person meetings with genetics providers. Although patient satisfaction was high, many sites dropped out for financial reasons.

In 2005, two insurance companies, Anthem and WellPoint, merged. One goal that emerged from this union was for every individual in Georgia to have access to a geneticist within 30 miles of home. The program has gone a great distance toward achieving this goal. The group transitioned to a non-profit model and established an open-access network model whereby a geneticist in the state can sign up to be a consultant to any site, anywhere in Georgia. The results have been impressive. The care provided to patients off-site seems to be comparable to that offered during in-person visits. Many sites offer scheduled “telegenetics clinics” that offer virtual genetics services. Additionally, urgent consultations are available, although infrequently used. And services are available to neonates, adding to the breadth of patients who can take advantage of telegenetics services.

. In Georgia, reimbursement is available for these services.

Telegenetics requires sufficient funding both at start-up and, consistently, during operation. In addition, rapidly changing technologies mean that considerable capital costs for new equipment or equipment modifications may continue to be incurred throughout the life of a telegenetics partnership. As with any high fixed-cost enterprise, volume determines ultimate sustainability, meaning that sites must continually reach out to new patient bases. However, there must be adequate funding and reimbursement for any expansion of telegenetics services. Whether funding comes from private enterprise or from government grants, it must be earmarked specifically for telegenetics. Reimbursement, in

particular, requires payers—whether private or public—to acknowledge the positive impact that telegenetics may make in the lives of affected patients. For many genetics patients, frequent follow-up appointments with medical geneticists are both necessary and potentially lifesaving. Although telegenetics partnerships may not immediately generate cost-savings, they are likely to be cost-effective if one factors in the significant expenditures of time, travel, and money that patients and families frequently are forced to make in order to receive competent genetics care from distant providers.

3. Recommendations

Funding agencies (including federal and state governments) should recognize the vital role that medical genetics providers play in the lives of affected patients and earmark additional funding to support new telegenetics efforts targeting those patients who live in medically underserved areas. This funding should acknowledge and provide coverage for long-term partnerships and take into account the fact that shifting technologies may mean continued capital costs throughout the life of any telegenetics venture.

Likewise, payers—both private and public—should recognize the contribution of geneticists to their patients and commit to reimbursing telegenetics services at a rate that allows for continuing sustainability. Payers should also commission studies to gauge the need for genetics services in underserved areas and target new partnerships accordingly. Finally, payers should study the cost-effectiveness of telegenetics and determine whether other telemedicine services can be provided along with genetics, using the existing infrastructure.

IV. Technology and Delivery of Telegenetics

1. *Background*

As with any telemedicine venture, proper information and communications technology are vital to the ultimate success of a telegenetics program. Recent advances in video conferencing, along with falling bandwidth prices, mean that telemedicine services can be made more broadly available, even in resource-limited settings, yet challenges remain. Prices for telemedicine equipment, though lower than in the past, still remain high and beyond the reach of many financially-strapped institutions. Unlike many other telemedicine services telegenetics requires high-definition video feeds. Since genetics practice often requires observation of minute dysmorphologies, the video connecting the patient and provider must provide sufficient detail to allow the physician to discern potentially abnormal features.

Greater technological innovation has brought its own set of delivery issues, including authentication of users and other data security and privacy concerns^{23,24}.

Telemedicine offers a potentially more effective and efficient method of distributing limited genetics resources. It promises to improve access, facilitate continuity of care from diagnosis to treatment, and provide public education networks for sharing knowledge. The use of information technology can provide virtual access to care for patients wherever they live, as well as facilitating education, training, and community-based participatory research. There are several examples of innovative approaches to the application of health information technologies and telemedicine to medical genetics in all regions across the country, as described throughout this white paper.

Of course, questions exist about whether telegenetics encounters conducted via webcam can ever match the accuracy and satisfaction rates of an in-person visit. Providers and patients alike must be comfortable with the video interface, which, by its nature, does not lend itself to the intimacy of in-person visits. Given the personal and often life-changing nature of medical genetics practice, concerns arise that this “disconnect” has the potential to lead to decreased satisfaction on the part of both the geneticist and patient. If both providers and patients are not satisfied with telegenetics experiences, there is a risk that parties will opt against more widespread adoption. On the other hand, some patients and family members may not be as intimidated by the “doctor in the room” when the doctor is present digitally through interactive video. In addition, many patients and their families are familiar and comfortable with electronic transfer of their records, their voices, and their images. They are accustomed to real time communication, and telegenetics may seem to them a logical extension of what they can do through their webcams, iPads, or iPhones.

2. *Proposals*

Many proposals exist to ensure that technology and delivery of telegenetics services meet the needs of both providers and patients. Expanded broadband internet access at both originating and distant sites has made synchronous (real-time) communication between provider and patient

possible. Nevertheless, bandwidth and capital costs continue to represent a large portion of telemedicine budgets.

At a national level, the government has the ability to direct broadband policy in such a way as to enable connectivity in rural areas. Moreover, entities such as the HSRA Office for Advancement of Telehealth (OAT) play a role in directing policy and, ultimately, clinical practice, through their grant-making activities.

3. Recommendations

The working group believes that Federal and state governments should continue their financial support for telemedicine generally and for telegenetics in particular. Organizations such as OAT play a vital role in the development of future telegenetics policy, and the ACMG, working in concert with other telemedicine professional societies, should collaborate with OAT to ensure that the appropriate technological infrastructure exists for continued telemedicine expansion.

The research community, too, should continue to investigate novel approaches to telegenetics practice. In particular, the working group recommends that existing research comparing the accuracy of physical diagnosis conducted in-person versus that done through telemedicine be continued and expanded to include a focus on diagnosis of genetic disorders that present with minute dysmorphologies. Additionally, telemedicine practitioners should work with user-interface designers to develop more efficient communication platforms from which to practice telemedicine. To the extent that these platforms can be customized to enhance the experience of telegenetics providers, they will lay the foundation for more medical geneticists to establish remote partnerships. Studies on the human factors in telemedicine (e.g. eye contact, speech [audio] delays, body language) should include the patients with genetic disorders including, but not limited to, Autism, Rhetts syndrome, and Huntington's Disease.

V. Future Directions

Telegenetics is still in a nascent stage of development. In order to ensure the field's growth, the recommendations set forth in this report should be adopted by the relevant governing bodies. However, these policy and institutional changes represent only part of what may be needed, which is likely to include activities in the area of both research and advocacy. Below are a few key areas in which telegenetics can continue to grow, given the proper framework.

1. *National Standards*

The American College of Medical Genetics & Genomics should continue to work collaboratively with other professional organizations such as the American Telemedicine Association, the Center for Telehealth and eHealth Law (CteL), the American Medical Informatics Association (AMIA), and the Health Information Management Systems Society (HIMSS) to harmonize approaches to facilitating the use of telemedicine to improve access to critical medical genetics services. Such efforts should include setting national standards and best practices in telemedicine and telegenetics. The standards should provide originating and distant sites with a roadmap on fostering an efficient and equitable telemedicine partnership. Each of the issues discussed in this white paper should be addressed, along with the need to ensure that patient and provider satisfaction with telegenetics services remains high. These organizations should also promote standards that encourage interoperability of competing technological platforms.

2. *Integration of Evolving Technology*

The professional telemedicine societies described above should encourage the adoption of new technologies in telemedicine and telegenetics. Just as high-definition video has made physical diagnosis more accurate and precise, technologies such as mobile handheld devices, remote monitoring, virtual reality simulations, and 3D holographic transmissions may lead to similar advances in telegenetics. Professional societies should adopt resolutions encouraging experimentation with and utilization of such technologies.

3. *Healthcare Disparities*

Despite the promise of telegenetics to bridge the gap between resource rich and resource limited settings, disparities in cost, quality, and access are likely to persist in the area of genetic services. The working group urges professional societies and telegenetics practitioners to continue research to identify underserved populations and work toward filling gaps in access to high quality, affordable genetics services.

4. Outcomes Research

The working group urges researchers to identify meaningful indicators to measure improved outcomes resulting from telegenetics consultations. Such indicators should be universal across all providers and patients, easily measured, and susceptible to intervention. Telemedicine researchers should also continue evaluations of telegenetics projects to gauge patient/provider satisfaction, assure accuracy of encounter results, and encourage innovations unique to the needs of

the population with genetic diseases. In particular, research should focus on studies that evaluate the cost-effectiveness and overall quality of telegenetics consultations as compared to in-person encounters. Another rich area for research is the cross-cultural acceptance of telegenetics services, including barriers to acceptance across a wide array of populations.

Creating Innovative User Interfaces

The need for streamlined technology is one of the many issues currently limiting broader adoption of telegenetics services. In particular, providers do not have an all-inclusive interface that allows for audio/video feeds, instant messaging, patient records, and note taking to be centralized and integrated. Some physicians and organizations have worked with software designers to solve that problem.

In particular, software has been developed that allows providers to interact with patients via a webcam. The software integrates the video feed and also allows simultaneous access to patient records and notes. Moreover, the software allows providers themselves to host videoconferences in which they can discuss a particular patient's condition. An overlooked area of telemedicine is the ability of providers to communicate with each other regarding the best course of management for a patient. This software, which has been used successfully in Louisiana, is a major step toward that goal.

VI. Conclusions and Recommendations

The working group believes that telemedicine, as a maturing healthcare technology, has demonstrated the potential to facilitate access to essential clinical services for underserved populations due to geographic location or limited numbers and availability of consultative specialists. Medical geneticists and genetic counselors currently are insufficient in number to meet existing patient requirements for genetics services. This disparity between needs and capacity is forecast to persist or worsen in the foreseeable future. Leveraging existing resources by means of communications technology can improve access to care, for the present and the future. Telegenetics can follow the successful model of other telemedicine applications to increase access to genetics services as a key component of improved healthcare, addressing the needs of underserved and/or geographically distant populations.

However, there continue to be significant barriers to the broad adoption and expansion of telegenetics. Before providers can establish reliable telegenetics partnerships with institutions in underserved areas, they must become properly licensed in the jurisdiction. At present, the administrative burden of obtaining and maintaining licensure in each jurisdiction is enough to deter many providers from establishing a telegenetics practice. And even where licensing is not an issue, such as for intra-state partnerships, credentialing issues often mean that providers may not be able to provide services to underserved patients. Without proper credentialing, reimbursement for services may not be possible. Issues regarding licensure, credentialing and privileging of professionals for the delivery of telegenetics services must be defined clearly and addressed promptly by appropriate regulatory bodies, so as to remove present impediments to telegenetics in multi-state settings.

The high start-up and legacy costs of operating a telegenetics venture may mean that many underserved areas will continue to lack adequate genetic services unless the government or private sector is able and willing to bridge the funding gap. Without adequate reimbursement for services, many telegenetics programs are not self-sustaining. Reimbursement rates must be adjusted to reflect the true cost of providing telegenetics services and take into account the overall cost-savings such partnerships provide over time.

Monitoring and assessment of the development, implementation, utilization, and effectiveness of telegenetics services is essential to ensuring continuous improvement of both systems and services. For example, there should be ongoing research into ways of optimizing the provider-patient experience by integrating new technologies. Appropriate and meaningful evaluation tools must be developed in order to provide a robust evidence base for the best practices in telegenetics.

Based upon these conclusions and as discussed in greater detail above, the working group recommends the following:

A. Licensure: The working group recommends adoption of a multistate licensure model featuring a mutually recognized telemedicine license. Under this system, a physician would file a single application and indicate those states for which he or she would like a telemedicine license. Such a telemedicine license would entitle the physician to practice in all the jurisdictions in which he or she obtains licensure. Any currently practicing physician with a

valid and unencumbered license would be eligible to apply. As part of the process, each state would agree to harmonize its own requirements for licensure, to the extent that such requirements differ today. The physician would agree to comply with the fee schedules, regulations, and educational requirements of each state for which he or she has applied for licensure. Ideally, those requirements could also be harmonized, greatly streamlining the licensure compliance process. The physician would also agree to submit to personal jurisdiction in each state in which he or she practices. In concert with this effort, states should also adopt a uniform definition of telemedicine and telemedical practice.

B. Credentialing: The working group recommends that credentialing for telegenetics providers be performed and recognized at a national level. Geneticists should be required to submit a uniform credentialing application to a central organization, which possesses the skills and institutional knowledge to properly evaluate and credential genetics providers. Such a national credentialing system could eliminate disparities in credentialing from institution to institution, and also work in concert with telegenetics efforts. National credentialing for genetics providers could also help foster a broader movement toward national credentialing for all medical professionals. A national credentialing system could rely on the Federal Credentialing and Verification System (“FCVS”) developed by the Federation of State Medical Boards. Privileging still will require appropriate alignment between the capabilities of the institution in which the patient is located at the time of the telegenetics consultation and those of the telemedicine providers and their institutions.

Absent a national credentialing process, the working group recommends that telegenetics providers be credentialed at originating sites by proxy. Such “proxy credentialing” relies on the due diligence and expertise of the distant site and allows the originating site to adopt that knowledge when authorizing geneticists to offer their services. Credentialing by proxy, as outlined by The Joint Commission, reduces the credentialing burden for the originating site, particularly in situations in which there may be large numbers of licensed, independent practitioners who would like to provide telemedicine services. Credentialing by proxy also reduces the administrative burdens faced by geneticists, as they need not re-submit their credentials and undergo verification at each originating site in which they establish a presence.

Finally, the working group recommends that the Center for Medicare and Medicaid Services (CMS) adopt either the national credentialing or the credentialing by proxy approach outlined above.

C. Financing and Reimbursement: Funding agencies should recognize the vital role that medical genetics providers play in the lives of affected patients and earmark additional funding to support new telegenetics efforts targeting medically underserved areas. This start-up funding should bear in the mind the long-term nature of partnerships and take into account the fact that shifting technologies may mean continued capital costs throughout the life of the telegenetics venture.

Likewise, payers—both private and public—should recognize the contribution of geneticists to their patients and commit to reimbursing telegenetics services at a rate that allows for continuing sustainability. Payers should also commission studies to gauge the need for genetics services in underserved areas and target new partnerships accordingly. Finally, payers

should study the cost-effectiveness of telegenetics and determine whether similar telemedicine services can be provided along with genetics, using the existing infrastructure.

D. Technology and Delivery of Telegenetics Services: Federal and state governments should continue their financial support for telemedicine generally, and telegenetics, in particular. Organizations such as OAT play a vital role in the development of future telegenetics policy, and the ACMG, working in concert with other telemedicine professional societies, should collaborate with OAT to ensure that the appropriate technological infrastructure exists for continued telemedicine expansion.

The research community should continue to investigate novel approaches to telegenetics practice. In particular, research comparing the accuracy of physical diagnosis conducted in-person versus telemedically should be conducted. Additionally, telemedicine practitioners should work with user-interface designers to develop more efficient communication platforms from which to practice telemedicine. To the extent that these platforms can be customized to enhance the experience of telegenetics providers, they will lay the foundation for more medical geneticists to establish remote partnerships.

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