

TELEMEDICINE MANUAL FOR CLINICAL GENETIC SERVICES

A 'How To' Guide for Starting a Telegenetics Clinic

Heartland Genetics and Newborn Screening Collaborative: Clinical Services Workgroup



HEARTLAND GENETICS SERVICES COLLABORATIVE

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I. INTRODUCTION

The Heartland Genetics and Newborn Screening Collaborative (Heartland) is a network of health professionals, policy leaders, laboratory personnel and advocates working together to promote and improve health through quality medical genetics services, clinical laboratory services, professional and public education, genetics research and public policy. Heartland is one of seven regional collaborative groups in the United States established by the Genetics Services Branch of the Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB/HRSA) as part of its ongoing effort to improve the health of children and their families. Heartland is made up of stakeholders from the fields of public health, clinical genetics, clinical laboratory services, consumer affairs, health care advocacy residing in eight Midwestern states (Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma and South Dakota). More information about Heartland can be found at www.heartlandcollaborative.org.

The Heartland Clinical Genetics Services Work Group strives to enhance services and increase the public's awareness of and access to genetic services. The workgroup identified telemedicine and its application to clinical genetics as a promising avenue for addressing current and anticipated deficits in the delivery of genetic services. The work group identified multiple successful efforts in telegenetics among its member states (see Appendix X).

This manual is a collection of resources and lessons learned from the collective experience of our eight states and literature about telemedicine. It answers some of the frequent questions encountered in the process of developing a telegenetics service. Some of the topics addressed include policies and procedures, sources of funding, information for patients, equipment, and billing. References and other resources are provided in the appendices. We hope this will be a helpful tool for establishing and sustaining a telegenetics program.

I.1 What is telemedicine?

Telemedicine is the use of telecommunications and information technologies for clinical services. It may be as simple as two health professionals discussing a patient over the telephone, or as sophisticated as using satellite technology to broadcast a consultation between providers at facilities in two countries, using videoconferencing equipment or robotic technology.

Telehealth is a broader term and includes telemedicine, electronic medical records, online drug pharmacies, and distance education for teaching and continuing education.

This manual will focus on telemedicine—providing medical genetics diagnostic, counseling, and management services using telecommunications technology.

For more information on terms in telemedicine, see the *Telemedicine Technical Assistance Documents* in Section 9.

1.2 Why use telemedicine to provide genetic services?

Advances in human genetics continue to reveal the influence of our genome on morbidity and mortality of common diseases. Most healthcare professionals have limited genetics knowledge and are insufficiently prepared to incorporate such information into their current practice. Genetics professionals, such as medical geneticists and genetic counselors, have specialized training and routinely provide specialized genetic services. However, there is currently a shortage of professionals providing clinical genetic services.¹ Thus, from the provider's standpoint, telemedicine can be an efficient mechanism for utilizing limited personnel.

Using telemedicine to offer healthcare consultations has many advantages for the patients as well. It can make specialty services accessible to underserved rural and urban populations. Video consultations can alleviate prohibitive travel and associated costs for patients. Family members may not have to take an entire day from work, and patients with barriers to access do not have to endure long and difficult trips.

Furthermore, for referring community providers, telemedicine technology opens up new possibilities for continuing education or training, for those who may not be able to leave a practice to take part in professional meetings or educational opportunities, and especially for a specialty such as genetics that many providers think affects a small percentage of their patient population. Moreover, telemedicine offers the opportunity for community providers to access the specialist on a case-by-case basis. Depending upon the setting for the telemedicine encounter (such as a newborn nursery in a rural hospital), the referring provider may even participate in the encounter thereby creating a "teachable moment" learning opportunity for that referring provider.

2. GETTING STARTED

2.1 Assess resources and needs

Most major medical centers, where genetics services are often based, utilize some telemedicine technology. Determining the extent of that technology, your access to it, the level of technology accessible to your community referral base, associated costs, federal, state, and institutional policies, and anticipating the impact of your new "telegenetics" program are first important steps. Planning can easily take six to nine months.

Answering the following questions will help you build your case and develop your proposal. These questions are then followed by practical suggestions for organizing the clinical and educational opportunities.

2.2 Self-Assessment

¹ Cooksey JA, Forte G, Benkendorf J, Blitzer MG. 2005. The state of the medical geneticist workforce: findings of the 2003 survey of American Board of Medical Genetics certified geneticists. *Genet Med* 7: 439-443.

Cooksey JA, Forte G, Flanagan PA, Benkendorf J, Blitzer MG. 2006. The medical genetics workforce: an analysis of clinical geneticist subgroups. *Genet Med* 8: 603-614.

When conducting a self-assessment it is very important to estimate the projected demand for services (i.e., volume and type) so that you can create a good financial model. This includes not only knowing current referral patterns for services, but modeling the projected demand types of services that would be amenable to your “telegenetics” program.



- Does a telemedicine program fall within or expand the scope and mission of your institution or your genetics program?
- What is the justification for developing a telemedicine program?
 - Did any particular event prompt this proposal? If so, describe; patient stories can be powerful and persuasive.
 - Where is your referral base? Graphics, such as a map or diagram showing your catchment area, can help decision makers visualize the need.
 - What is the distance, in time and miles, to clinical services for your patients?²
 - What percentage or number of your patients lack reliable transportation and must depend on public transportation (such as Medicaid transportation in rural areas), friends, family, or church members to drive them to appointments?
 - Who comprises your referral base? Are there particular groups of patients not accessing services for a reason that telemedicine would alleviate?
 - Is the goal to expand the current catchment area beyond its present borders, or are there gaps within the catchment area that need to be addressed?
 - Are traditional outreach clinics being replaced or are genetics services being expanded through telemedicine?
 - Will this reduce or increase costs to the Genetics section budget? If telemedicine is replacing a traditional outreach clinic, will costs increase or decrease? (See Section 2.1.4)
 - Do your patients and referring providers have an interest in a telemedicine program? (A survey may identify some of the transportation issues among your patients and may identify patients that local providers have not referred for a variety of reasons).
 - How would a telemedicine program meet the identified needs?
 - What is the expected outcome?
 - How will you know if the telemedicine clinic is successful?
 - Do you have buy-in from your administration and clinical team to use telemedicine for patient care?
- What resources already exist at your institution?
 - Does your institution have any telemedicine program? (If so, contact them first. If not, proceed to address the remaining questions).

² <http://www.ncbi.nlm.nih.gov/sites/GeneTests>
ACMG GIS

- Who will be able to assist you and your staff (termed the distant site and defined in section 2.1.2) when technical difficulties arise? (See Section 2.1.2)
- What resources exist in your state, such as a state telehealth program?
- What resources exist at the originating site(s)? (See Sections 2.1.2 and 2.1.3)
 - Who will be able to assist the patient at the originating site? (originating site is defined in section 2.1.2)
 - Who will be able to help you and your staff when technical difficulties arise at the originating site?
- Will additional staff be needed or will you be able to accomplish the objectives with existing staff, possibly even with fewer staff? (See Section 2.1.2)

2.2.1 Staffing Assessment

Staff requirements will depend on the size and type of clinic and procedures to be performed. The personnel identified below include all possible participants. Rarely will a telemedicine clinic have the luxury of involving all of these team members.

- Distant Site (other names: hub site, specialty site, or referral site)
 - Geneticist
 - Genetic Counselor
 - Dietician and other allied health, as needed
 - Network Trainer*
 - Technical support
 - Billing and coding specialist informed about telemedicine reimbursement



*The network trainer will teach the staff how to utilize the equipment and will be in the room during the first few visits.

- Originating Site (other names: spoke site, patient site, remote site, or rural site)
 - Telemedicine services coordinator
 - Nurse or medical assistant to obtain vitals
 - Genetic counselor or nurse to assist with physical examination, education, counseling, and case management
 - Technical support (on call)

Involvement of staff at the originating site will vary with their understanding of and commitment to telemedicine, availability of interested and trained personnel, and perception of benefits to patients, staff, and the institution.

2.2.2 Originating Site Assessment

- Where will the originating site(s) be located? Choices typically include hospitals, private offices, county health offices, federally funded health centers, and interdisciplinary clinics. If your institution has a telemedicine program, they most likely have a network of originating sites that you can use. (This edition of this manual excludes telehealth conducted in the patients' homes.)
- Identify the stakeholders (physicians, nurses, administrators, patients or relatives).
- Meet face-to-face with those stakeholders at the originating sites to assess local need. Each individual originating site must be addressed.
 - Determine the benefits and drawbacks of using telemedicine perceived by each originating site. Providers are more likely to utilize the telemedicine service (refer patients) if they recognize an advantage for themselves.
 - Surveys, key informant interviews, and focus groups may first be used to find out the types of services providers want (for example consultation only, return patients only, medically or socially urgent patients) and the types of conditions they would routinely refer.
 - If staff at the originating site feels at all uncomfortable about having services provided via telemedicine, the project will not succeed. Identify the source of this discomfort and see if it can be addressed through demonstrations, training, listing of benefits, etc.
- Identify the technology needs at the originating site (See Section 2.1.5).
- Assess the physical space where the patient will be. Acoustics of the room, environmental sounds (street noise, overhead speakers, etc.), and lighting can affect the quality of the physical assessment and the session in general. (See Appendix VI)

If you are unable to have a telemedicine coordinator at the originating site, then make arrangements with the originating site for someone (office manager or receptionist) to welcome the patient, copy the insurance card, obtain vitals, and settle the patient into the telemedicine room, arrange and orient to camera and microphone.

2.2.3 Economic Assessment

- Consider start-up expenses at the distant site and all originating sites, including hardware and software, peripheral devices and equipment, and special personnel. (See Sections 2.1.2 and 2.1.5).
- Be sure to consider the maintenance costs (e.g., room rental, line charges, etc.).
- Personnel costs may include a clinic coordinator, nursing staff and information technology staff at the distant site and all originating sites.
- Negotiate with the originating site regarding division of expenses. If your institution has an established telemedicine network that you will be using, negotiation of costs is unlikely to be an issue. In the absence of such a network, consider factors such as whether the originating site will provide a consistent referral stream. If so, then the distant site may be willing to cover costs. Alternatively, the originating site may agree to cover all or partial costs since the telemedicine clinic will enable their patient evaluations and treatment to take place locally, bringing in more revenue if tests or procedures are ordered. Another factor for many larger institutions is building goodwill in the referral base, which telemedicine clinics can do.

- Assess and negotiate reimbursement for professional services.^{3,4} This may include billing for services or a fixed price outlined in a contract.
- Know the payer mix of the patient population to be served by that telemedicine clinic and determine the expected reimbursement based upon that payer mix.
- Consider the patients' expenses. Direct and indirect costs relating to travel are significant and frequently overlooked. This expense is not covered by insurance, but may be an expense to Medicaid because of mandated transportation services for certain categories of patients. Consider collecting qualitative data regarding the convenience that it affords the patients/families.

2.2.4 Technology Assessment

- Check with your institution regarding existing telemedicine infrastructure available for your use at the distant site and if there exists a network of originating sites.
- What type of broadband connection exists between the distant and originating sites? Broadband is high-speed transmission of audio and video information and is needed for most telemedicine applications. Types of broadband connections included digital subscriber line (DSL), cable, fiber, wireless, satellite, and broadband over power lines.^{5,6}

The FCC defines broadband as a transmission rate of greater than 200kbits/sec. Some would see this range as less than true broadband. For effective 'real time' transmission rates of greater than 1.5megabits/sec are desirable. Suggested rates to consider in planning would include:

- A recent FCC broadband report recommends 4 megabits/sec for single physician offices.
- However, much of telemedicine can be done at 1.5 or even half that speed, especially videoconferencing based applications.
- An exception may be genetic counseling only, which would not necessitate the same level of resolution.
- Inventory the technology and determine the network infrastructure available at each originating site.

³ Reimbursement is available via Medicare as well as Medicaid in many states (see Telemedicine Reimbursement Report, Telehealth Publications, Health Resources and Services Administration (HRSA) at: <http://www.hrsa.gov/telehealth/pubs/reimbursement.htm>). Insurance providers will usually follow the lead of Medicare and Medicaid and also provide reimbursement.

⁴ Additional reimbursement information is available from the Center for Telehealth and E-Health Law. <http://www.telehealthlawcenter.org/?c=117>

⁵ See Federal Communication Commission, *What is Broadband?* <http://www.fcc.gov/cgb/broadband.html>

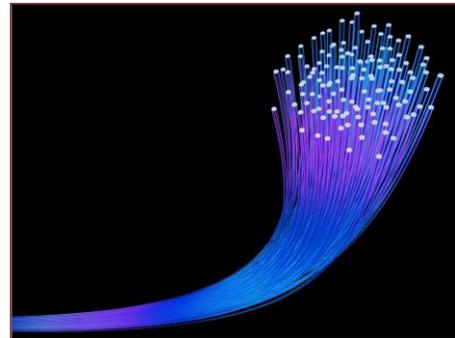
⁶ Go to the Universal Service Administrative Company (USAC) website for general information and to "selected participants" in the Rural Health Care Pilot Program to determine rural health care funding specific to your state (<http://www.universalservice.org/rhc-pilot-program/tools/selected-participants.aspx>) Seven of the eight states in Heartland received funding under this program in 2007-2008—AR, IA, KS, MO, ND, NE, and SD.

- Determine if any peripheral devices will be needed (e.g., digital otoscope, electronic stethoscope) or if an on-site practitioner will perform examinations during consultations.⁷
- Where is the telemedicine unit located at your institution? In your clinic or elsewhere? If a telemedicine unit is located in another building or on a different floor, then the probability that it will be used is lower.

2.3 Telemedicine equipment

Several pieces of equipment are required in using telemedicine. At a minimum, an originating site connection will need to be established using an Integrated Services Digital Network (ISDN) or a Digital signal 1 (T1) line with a bandwidth large enough to handle the amounts of data being transferred. Conferencing equipment such as a web camera or viewing station, monitor, DVD or VCR to record the session⁸, and associated cabling supplies should be available at both sites. Telemedicine, telecommunication equipment, “lines,” and connectivity are constantly changing—they are moving targets. This is good news because it means technology is improving and becoming more affordable. Depending on clinical need, it may also be necessary to have access to a high-resolution digital camera and diagnostic equipment.

In order to conduct telemedicine, including genetics and dysmorphism, the appropriate equipment must be available, usable, and working. Typically this involves ITV (interactive television) equipment at both distant and originating sites, including a monitor, a unit with attached video camera and microphone (Polycom© and Tandberg© are two main companies), as well as an ISDN or T1 connection with a minimum of 128 kilobits per second (kbit/s). When selecting equipment, one of the major considerations is the quality of the equipment.



Higher resolution cameras improve the quality of the images and enhance the ability of the consultant to visualize more detail on the examination. It is important to remember that higher resolution is associated with more pixels (i.e. more data), which requires higher bandwidth capacity to transmit images in the same time as compared to lower resolution images. Thus the key to resolution is higher quality cameras and higher bandwidth capacity. Cameras used with the equipment are made to automatically focus on the person who is

⁷ A list of telemedicine vendors for this special equipment is located on the American Telemedicine Association website, (<http://atatelemedicinedirectory.com/index.php?>).

⁸ Note: Recording a session is optional. In one sense, recording of sessions and including the recording in the EMR in theory represents the most complete documentation of a patient encounter. However, there is no consensus at this point as to the potential medical-legal ramifications of such documentation. Should the originating site choose to record and save the session, several policies need to be maintained: 1) The recorded materials should be appropriately encrypted, 2) All standards of patient confidentiality should be maintained, 3) The same standards and guidelines for record keeping of other forms of EMRs must be followed including HIPPA, etc. It should be anticipated that using new technologies will make it more complicated for the medical records system to adhere to established standards – as new efforts always seem to challenge systems.

currently speaking and are controllable at each end. Cameras need to be able to zoom for accurate examinations.

There is a large range of available add-on equipment, such as an electronic otoscope stethoscope, dermascope, Wood's lamp, sonographic and radiological equipment, and digital cameras. Such equipment is quite expensive to purchase, but can significantly add to the quality of the assessment, especially when a trained provider (genetic counselor, nurse, physician, etc.) cannot be present with the patient.

Therefore, ideally a medical genetics service would not take on the full cost of the interactive video lines and the video units, but rather shares these costs, in addition to covering the costs of the line charges used during the visits. In many states, the necessary equipment is in place, but has not been utilized for genetic services. It is always easier to start a medical genetics clinic at a site that is already set up and using telemedicine equipment.

Due to the war on bioterrorism, many hospitals and clinics are equipped with T1 lines [You need to define T1 lines earlier or here depending on where you are first going to introduce T1 lines bandwidth -- 1.5 megabits/second.] and interactive video equipment. The administrators of those programs may be protective in the beginning, wanting to reserve their use for emergencies only. However, they can soon be convinced that it is better to use the equipment in order to be sure it is working and that the staff is familiar with the equipment in time of emergency. During an emergency, the lines can be assumed by higher priority federal or state agencies.

3. POLICIES

As an alternative medium for patient-provider interaction, successful telemedicine programs operate within the bounds of policies and procedures created to protect and enhance all exchanges between patients and providers. There is over 20 years of experience in the United States in developing successful telemedicine programs and no one should have to start from scratch. Established policies and procedures have been developed and are available for adaptation to a particular program's structure. In our experience, unrestricted information and resource-sharing are common practices among telemedicine providers, national groups such as the American Telemedicine Association (ATA), and government programs (see Section 9). However, each telemedicine partnership may want to adapt existing policies to best fit the specific needs and services it is addressing. These policies may be written by the designated professionals within the hospital staff, employed or contracted attorneys, or members of the clinical genetics staff itself. However, the final product should have a formal legal review prior to implementation.



Privacy issues and confidentiality are very important. All clinical telemedicine encounters must uphold the same HIPAA⁹ standards as a traditional, in-person clinic appointment. The telemedicine units need to be located such that health information can be shared and physical examinations conducted in privacy. Pediatric patients are usually at ease and find it fun to be “on TV.” Adult patients are fairly comfortable except for examination of private areas of the body. In this circumstance, it is ideal if the providers involved in the session are of the same gender as the patient. Reassure the patient that the equipment, software and connections have built-in proper encryption that meets clinical practice standards set by HIPAA. It is important that you determine if your network is compliant all patient information needs to be encrypted and stored utilizing accepted standards for security. or if images need to be encrypted Data should be encrypted for purposes of transmission and/or storage. Transmission of images must meet all HIPAA guidelines. Finally, remember this rule-of-thumb: security and confidentiality issues are no different than those of a routine genetics appointment.

Additionally, having a small number of staff involved directly with the patient can make them feel more comfortable. The geneticist or genetic counselor at the distant site should always identify any additional team members with them (genetic counseling students, medical student, dietician, etc.) because the camera angle or location of the providers in the room may prevent the patient at the originating site from seeing everyone.

3.1 Licensure and Privileging

A critical consideration when planning telemedicine services is the necessity of securing all of the authorizations needed to provide those services. In general, the originating site (where the patient is) is considered the site where the service is being provided. As such, a medical practitioner will need a medical license for the state in which the patient is located. In addition, if the originating site is in a health care facility that requires privileging of the telemedicine provider, the telemedicine provider must secure those authorizations as well. This is one of the most limiting hurdles in providing outreach services. If a distant site wishes to provide outreach to 20 sites in another state, that practitioner will need to procure a license in that state, including having his or her credentials verified, and be granted privileges to practice at each of those 20 sites. This effort represents a tremendous amount of paperwork, time and money. Still, it is absolutely necessary to do so. Efforts are being made for legislation and regulations that will allow more universal authorizations. For further information, the reader is referred to the FCC’s Connecting America Plan (<http://www.broadband.gov/>).

3.2 Risk management

The issue of malpractice and liability is very complex in relation to telemedicine. The main reason for the complexity of the issue is because it has not been determined where the site of care occurs.

⁹ <http://www.hhs.gov/ocr/privacy/>

Asking the following questions can help identify key considerations in liability.¹⁰

- In what state is the patient located?
- In what state is the physician located?
- From which medical board(s) and hospitals has the physician obtained either licensure or credentialing?
- Does either state have telemedicine laws that increase physician requirements and standards when conducting telemedicine sessions?
- Is the use of telemedicine providing the same standard of care as a face-to-face appointment?
- Does the physician's malpractice insurance cover the telemedicine act in question?

Clinicians can use a variety of tools to manage liability in providing telemedicine services including the use of a separate consent form for the telemedicine session or retaining a videotape of the session as part of the permanent medical record for that patient. Geneticists are encouraged to contact their malpractice insurance carrier and institution's legal department for guidance.

4. PROCEDURES

Procedures will vary depending on the providers, the type of medical genetics clinic to be held (e.g., metabolic consultation, dysmorphology examination, or other) and the characteristics and resources of the originating site. Keep in mind that you may need to develop procedures that are specific for each originating site. Over time, however, providers realize that telemedicine medical genetics clinics are very similar to on-site medical genetics clinic because telemedicine is only a tool, not a medical specialty.



The authors' collective experiences indicate that providers are more apt to incorporate telemedicine clinics when originating patient appointments are part of the providers' regular clinic schedule. If possible, designate a "telemedicine room" at the distant site. The originating site patients have appointments that fit into the distant site's regular genetics clinic schedule. The geneticist enters the "telemedicine room" when that patient comes up on the schedule.

Most accomplished telemedicine professionals began with "on-the-job training" experiences. Should you wish to have some specific instruction, numerous informational meetings occur every year. Alternatively, on-site consultation, or making a visit of your own are options. You can contact or visit others within the Heartland by scanning the list of telemedicine providers in Appendix X.

¹⁰ Telemedicine: Survey and Analysis of Federal and State Laws by Thomas W. Mayo, and Tara E. Kepler. Chapter

As in a face-to-face appointment, someone must also obtain and evaluate a three to four generation family history. Typically, this interview could be done by a genetic counselor at the originating site, a genetic counselor over videoconference from the distant site, or a specifically trained on-site nurse. It could be done by telephone prior to the day of consultation or even the same day. When a signature is required (e.g., consent for genetic testing or release of health information), someone at the patient site must be able to access requisition forms, consent forms, and obtain the necessary signatures. A plan should be made with the patient as to how they would like to receive the results of any genetic testing (e.g., over telemedicine, phone, letters, etc.).

A remedy to most, if not all, of the potential problems with telemedicine is hiring a telemedicine services coordinator. Many large telemedicine programs now have a telemedicine services coordinator whose role is a combination of parts from the roles of the clinic nurse, specialty nurse, case manager, outreach social worker, administrator, and public relations professional. If you do not have a telemedicine services coordinator, the following job duties must be assigned to other staff.

4.1 Telemedicine services coordinator

A telemedicine services coordinator can be the key to the success of a medical genetics telemedicine clinic. The coordinator may or may not be employed by the distant site. In addition the coordinator may or may not be at the originating site with the patient. Responsibilities include developing telemedicine clinic schedules, introducing staff members, patients and families to telemedicine, and working with billing and IT staff to provide an efficient program. (See Appendix I)

Although some would say it is not mandatory, it is our strong contention that funding for a telemedicine services coordinator should be secured if at all possible. Services really require more than just standard “business office” services. The skills and time of a telemedicine coordinator depend on the intake and scheduling system, number of patients, providers, clinics, and originating sites, and the complexity and dependability of equipment and connections.

Telemedicine services coordinator responsibilities include but are not limited to the following:

- Serving as the point-of-contact for the genetics clinic and representing the genetic faculty and staff.
- Scheduling patients into the clinic slots as agreed upon between both sites.
- Updating the genetics office, by fax and phone, of any schedule changes.
- Turning the equipment on and check-in 15 minutes prior to the consult or educational presentation.
- Ensuring patients and participants complete the evaluations at the conclusion of the clinical or educational presentation.
- Keeping a supply of clinic forms, evaluations and sign-in sheets at originating site.
- Preparing the patient and family as to how the equipment and connectivity work and what to expect from the clinic session.
- Disseminating any information, flyers, handouts, etc. as appropriate for each patient and family.

- Scheduling blood draws locally, providing lab request forms, for genetic tests as requested by the geneticist or genetic counselor.

4.2 Conducting dysmorphism and physical examinations

Conducting a physical examination via telemedicine is the decision of the physician. If the physician is new to telemedicine, then it is recommended that he or she begin with consulting, follow-up or counseling only. Once the physician is more comfortable with the technology and logistics of the patient being at an originating site, and if the equipment and connections deliver the requisite quality, then the physician may experiment with physical examinations via telemedicine. The patient can always be told when the telemedicine appointment is made, that he or she may have to travel to the distant site if the physical examination is not adequate via telemedicine.

Physical Examination at the Originating Site

- Patient preparation at the originating site:
 - Patient should arrive 15 minutes early to gather and sign consent and HIPAA forms and collect vital signs. As with regular clinics, measurements should be plotted in standard growth curves, ideally with historical points.
 - Gowning may be required depending upon the indication for evaluation and physician preferences.
 - Center patient in front of camera.
 - The originating site healthcare provider should have any special equipment, scopes, or cameras ready and be familiar with their use.



Physical Examination at the Distant Site

- Physician responsibilities (or his or her designee):
 - Connection to originating site initiated.
 - A limited physical examination is performed by zooming in with the camera and viewing patient's head, hands, eyes, mouth, back or any area of concern.
 - Geneticist may direct the originating site healthcare provider in handling, moving, directing, or focusing any of the special equipment.
 - Geneticist may request the patient to stand and move around to view posture, balance, movement, and gait.

If you have a telemedicine services coordinator, nurse, or genetic counselor, then those professionals may remain in the room with the patient, and be available to perform a physical examination at the request of the geneticist.

4.3 Patient satisfaction with the telemedicine genetics clinic

A significant body of literature exists that attests patients being highly satisfied with their telemedicine experience.¹¹ Thus, it is not necessary to conduct patient satisfaction surveys in order to evaluate telemedicine in general (i.e. is telemedicine agreeable to patients?). However, if your practice routinely uses patient satisfaction surveys in its distant (or local) clinics, it would make sense to do so for telemedicine visits also. If the telemedicine clinic is new, it is always good to conduct patient satisfaction surveys in order to receive feedback and make improvements. It might also be helpful to collect information about clinician satisfaction, at both the originating and distant sites. Little information currently exists for this venue, and most would consider this aspect of providing services as ‘not fully evaluated’.

4.4 Interdisciplinary clinics

Interdisciplinary clinics represent an additional level of complexity in providing patient care. Clearly these types of clinics provide a myriad of advantages for the patient and their family. Ideally, it would be of great utility for patients and their family if such specialty services could be provided by distance methods.

The question then is “can interdisciplinary services be effectively provided by telemedicine”? Experience from multiple sites suggests that, indeed, they can. First-hand experience at the University of Nebraska Medical Center was notable for the effective offering of a “medical transition clinic” with six specialists for complex patients at great distances – even utilizing a language interpreter as part of the telemedicine offering.



In general, the major consideration is the structure of the interdisciplinary team. Specifically, patient flow is the key issue. Interdisciplinary clinics typically operate under three potential models:

- 1) The team members remain in their assigned room and the patient is moved from room to room, seeing each team member for their own visit.
- 2) The patient remains in a single room and the team members rotate entering the same room with the patient.
- 3) The patient meets with the entire team in a large conference room at a single session.

The second and third options are easily amenable to telemedicine services. The first protocol is more difficult (but not impossible) as the telemedicine equipment at the service provider site must be moved within the clinic.

Otherwise, interdisciplinary services really present very few, if any, additional problems beyond that of single service providers. The rationale for inter-disciplinary services is enhanced for

¹¹ Herendeen NE and Schaefer GB: Practical applications of telemedicine for pediatricians. *Pediatr. Ann.* 38(10): 567-569, 2009

telemedicine. Complex patients needing access to multiple specialists – often located at great distances - greatly benefit from such clinics which otherwise may be impossible to obtain.

5. FINANCIAL CONSIDERATIONS

Equipment will be required at both ends of the transmission. As with most electronic technology, the range of expense will depend upon all of the options and specifications that are desired. In general, the system includes monitors, the core transmission system, and any particular add-ons. Particularly for telemedicine services, the types of cameras that need to be used (high resolution medical cameras); document readers, x-ray readers, and potentially even telemedicine stethoscopes may be needed. In general, the systems can cost anywhere from \$8,000 to \$50,000. Once the initial equipment has been purchased, there may be recurring costs such as line charges. As with most technology based purchases, prices for telemedicine equipment are dropping and should continue to do so. Even high definition video conferencing is becoming much more affordable with the entrance of several alternative low cost solutions.

5.1 Billing and reimbursement

Billing for telemedicine services may be particularly confusing. Clearly the answers to these questions are often going to be specific to your system. Still, several principles help in setting up appropriate billing protocols. Key to successful reimbursement is to learn the guidelines your patients' payers have regarding telemedicine.

Most payers consider telemedicine services to be conducted as if the distant provider is sitting in the room with the patient at the patient's locale. Therefore, a bill may be generated by the distant provider for the appropriate level of services as if they are in the room with the patient. Depending upon the rules and regulations of the particular payer, the same billing codes may be used as in standard clinics. A GT modifier is often added to the billing codes to clearly identify a service as being provided via telemedicine.



Many payers will allow a bill from another health care provider at the patient (originating) site who may aid in the examination and presentation of the patient. Additionally, a facility fee is typically charged, which may be an allowable charge for the use of the telemedicine site – at the originating site. Typically, however, facility fees are not allowable for the provider's (distant) site of service provision.

A comprehensive guide to billing and reimbursement can be found in the document, Medicare Payment of Telemedicine and Telehealth Services, May 15, 2006 at http://www.americantelemed.org/files/public/policy/Medicare_Payment_Of_Services.pdf

Medicare has approved a formula for developing a 2009 physician fee schedule for physicians/non-physicians that provides care to Medicare beneficiaries over telemedicine.¹² A fact sheet from the Centers for Medicare and Medicaid Services (CMS) is also available providing an overview of Medicare part B services.¹³ Medicare only reimburses for services provided to patients in rural originating sites and the types of services are limited.

Medicaid may reimburse for telemedicine, if the telemedicine from an individual state application satisfies “federal requirements of efficiency, economy and quality of care.”¹⁴ States have leeway in funding telemedicine, and any state wishing to cover or reimburse for telemedicine services can submit a State Plan Amendment to CMS for approval. Each state thus develops its own set of telemedicine ‘rules’ for Medicaid. Before beginning services, the originating site should verify what the specific Medicaid reimbursement policies are for that state.

5.2 External funding

Telemedicine grants may be obtained from federal, regional, and local sources as well as private funds. Grant funding is particularly helpful for the seed money needed for the initial purchase of the equipment.¹⁵

- A few sources of funds may include:
 - Maternal Child Health Bureau <http://mchb.hrsa.gov>
 - Office for the Advancement of Telehealth www.hrsa.gov/telehealth
 - Office of Rural Health <http://ruralhealth.hrsa.gov>
 - Medicaid/Medicare www.cms.hhs.gov
 - Federal Communications Commission <http://www.fcc.gov/cgb/rural/rhcp.html>
 - Department of Agriculture's Distance Learning and Telemedicine Program <http://www.usda.gov/rus/telecom/index.htm>

The crucial issue for a sustainable service is the ongoing costs, not equipment costs. Once the initial costs have been incurred for the equipment, telemedicine services can be sustainable on a fee-for-service basis.¹⁶ However, many programs do struggle with developing sustainable business models for many services. Examples of strategies that some programs have used successfully include membership models, contractual services, etc, and not simply fee-for-service.

¹² Centers for Medicare & Medicaid Services > Medicare > Physician Fee Schedule at <http://www.cms.hhs.gov/PhysicianFeeSched/>, page last modified 09/02/2009

¹³ Centers for Medicare & Medicaid Services <http://www.cms.hhs.gov/MLNProducts/downloads/TelehealthSrvcsfctshd.pdf>

¹⁴ Centers for Medicare & Medicaid Services > Medicaid > Telemedicine > Overview, at <http://www.cms.hhs.gov/Telemedicine/>, page last modified 04/15/2009

¹⁵ For a list of government agencies that have grants for telemedicine, visit the website for Telemedicine Information Exchange (TIE), an unbiased and all-inclusive platform for information on telemedicine and telehealth <http://tie.telemed.org/funding/news.asp>

¹⁶ Herendeen NE and Schaefer GB: Practical applications of telemedicine for pediatricians. *Pediatr. Ann.* 38(10): 567-569, 2009

6. PATIENTS' FREQUENTLY ASKED QUESTIONS

As is true for providers, patients also tend to be uncomfortable with new technologies. Telemedicine providers should be prepared to answer patients' questions. Below is a compilation of the most frequently asked questions from our collective experience:

- Who are the team members?
- Will the video be retained? If so, who will have access and where will it be stored?
- Are telemedicine connections secure?
- Is an evaluation via telemedicine as good as a face-to-face visit?
- How will I know what to do?
- What information do I need to bring?
- What about different time zones and work schedules between locations?
- Where are the clinics located?
- How does telemedicine work?
- Is the equipment reliable and maintained?
- What about failed connections?
- Is it “real time” or are there lags in transmission times?
- Where do I look when I am talking to the specialist?
- Will it cost me more or less?
- Will my insurance cover a telemedicine consultation?



7. LESSONS LEARNED

- Start small:
 - Start slowly – nothing disrupts the process and discourages the team more than a bad start. Start with a single patient to see how it goes and then proceed. In the early stages, it is important to have personal contact ahead of time.
 - Start with an established patient.
- Obtain and maintain buy-in of all stakeholders:
 - Traveling to the originating site, engaging the local staff, and working out any bugs really seem to reduce the potential for problems down the road.
 - It cannot be over-emphasized how critical it is to establish strong connections at the distant sites. Everything can be established and organized at your end, but without strong support at the distant site, it is unlikely that you will be able to establish a site that has long-term sustainability. It is particularly useful to identify – if possible – a local “champion” for your telegenetics services. It is better if this champion has a significant presence in the local medical community (as well as a healthy interest in genetics).
 - Programs are often hampered because they do not address the need for depth in staff at both the originating and distant sites. Continuous training of key staff at both the originating and distant sites will help solidify your staff and may reduce staff turnover.
 - It is important that the program develop from service needs and not because of new technology or surplus funds.

- Telemedicine service coordinator at the originating site is beneficial for the patient as well as the distant site team:
 - Enough cannot be said regarding the benefits of having a telemedicine service coordinator or health care professional at the originating site with the patient. This tends to ease the patient by having someone with them. In the situation where this is not possible, at a minimum, an on-site staff person will be needed to provide instructions so that the patient can successfully maneuver the equipment during the session.
 - Before the session begins, orient the patient to the evaluation and the technology. Many will not have experienced this type of medical appointment before and will not know what to expect.
 - Take time before the appointment to become familiar with the equipment, especially the camera to make the session run smoothly. For example, find the best place to stand to do the examination without blocking the camera but still be able to use the equipment.
 - The families are usually as comfortable as the staff makes it for them. Train the physicians themselves to use telemedicine and show them the benefits of telemedicine.

- Location, location, location:
 - It is important to locate telemedicine equipment in rooms close to the physician at the distant site for easy access.
 - Is the clinic facility located in an area of town where the patients feel comfortable traveling?

- Tips for good visibility:
 - Room characteristics such as background, elevations of camera and lighting are very important for physical examinations. (See Appendix VI)
 - More than three people in a room make it hard to view everyone on the monitor.

- Telemedicine can save time:
 - Patients and families like telemedicine, and usually, their appointments are scheduled sooner than at the distant site genetics clinic, which saves time.
 - Physicians, too, save time if telemedicine clinics replace traditional outreach clinics.

- Telemedicine can be cost effective:
 - After the initial investment of equipment, in general, we have found telemedicine services to be “break even” on services. Specifically, telemedicine services can be as cost effective as similar services provided in person.
 - Patients and families like telemedicine, and usually, their appointments are scheduled sooner than at the distant site genetics clinic, which saves travel dollars.

- Physicians, too, save travel expenses if telemedicine clinics replace traditional outreach clinics.
- In order to make telemedicine economically feasible, scheduling is the prime issue. These visits cannot be scheduled at intermittent times. Essentially, providers need to have true scheduled “clinics” where blocks of time are allocated so that they can see multiple patients in a day. There are several ventures using this approach that have proven cost effective at the private practice level.¹⁷

In summary, key components to the success of a telemedicine program include:

- ability to control costs for patient;
- ease of use for patients;
- comfort level of the provider and patients;
- quality of transmission;
- convenience for provider and patient; and
- ability to utilize the technology for varied encounters (prenatal, preconception, dietician and metabolic patient, hereditary cancer genetic counseling, and patient support groups, etc.)

8. CONCLUSION

Telegenetics (medical genetic services provided at a distance via electronic connections) is designed to greatly enhance genetic services and education in your genetics program. Everyone benefits. The medical specialist is promoting quality outreach service thereby increasing provider access and awareness. The originating site (rural site) benefits by providing access to patients and families close to home and economically from specialist utilizing local lab and x-ray services. The patient and families are provided with outreach services that they might not receive because of the expenses associated with traveling to distant site (hub site) and missing work to attend clinic.

The goal of telemedicine outreach services is to add to existing face-to-face clinics and provide access to genetic services to rural patients and families. It may also be used for physician consultations and education for families and the health care community.

In short, any clinical service that can be provided face-to-face can be easily provided by telegenetics, truly! As with any new methodology, there is some up-front work to establish the network and to provide integration and coordination among differing units. After the initial investment you will realize the benefits of scheduling flexibility, controlling patient costs and relationships you build with rural communities. The added dimensions of these services along with the elimination of many significant barriers for the patients and their family’s makes telegenetics a “value added” service. In our opinion telegenetics is a win-win-win for everyone!

¹⁷ Herendeen NE and Schaefer GB: Practical applications of telemedicine for pediatricians. *Pediatr. Ann.* 38(10): 567-569, 2009

9. TELEMEDICINE RESOURCES

- American Telemedicine Association: <http://www.atmeda.org>
- Telemedicine Information Exchange: <http://tie.telemed.org/>
- Center for Telehealth & E-Health Law: <http://www.ctel.org/>
- Maternal Child Health Bureau <http://mchb.hrsa.gov>
- Office for the Advancement of Telehealth www.hrsa.gov/telehealth
- Office of Rural Health <http://ruralhealth.hrsa.gov>
- Medicaid/Medicare www.cms.hhs.gov
- Federal Communications Commission <http://www.fcc.gov/cgb/rural/rhcp.html>
- Telemedicine Technical Assistance Documents:
<http://telehealth.muhealth.org/general%20information/getting.started.telemedicine.pdf>
- Doolittle GC, Spaulding RJ. Defining the needs of a telemedicine service. J Telemed Telecare. 2006; 12(6):276-84

10. APPENDICES

- I. Sample Job Description—Telemedicine Services Coordinator
Source: University of Missouri—Columbia
- II. Sample Policy and Procedure Document
Source: University of Nebraska Medical Center
- III. Sample Patient Consent Form
Source: Missouri Telehealth Network
- IV. Sample Telemedicine Budget
Source: UAMS Center for Distance Health
- V. Sample Encounter Form
Source: Missouri Telehealth Network
- VI. Telehealth Room Recommendations
Source: Missouri Telehealth Network
- VII. Telemedicine Tracking and Quality Assurance Form
Source: University of Arkansas for Medical Sciences
- VIII. Telemedicine Clinic Log
Source: Missouri Telehealth Network
- IX. Telemedicine Satisfaction Survey
Source: Missouri Telehealth Network
- X. Telemedicine and Telegenetics in Heartland States
Source: Heartland Genetics and Newborn Screening Collaborative