Highlighting Family Perspectives on Telegenetics

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National Genetics Education and Family Support Center

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Housekeeping

- This webinar is scheduled to last 1 hour, including Q&A.
- All dial-in participants will be muted to enable the speakers to present without interruption.
- The webinar is being recorded and will be sent via email with the slides, infographic and a brief evaluation survey after the live presentation.
- Questions can be submitted via the chat function at any time during this presentation. We will have a dedicated time to answer questions at the end of the presentation.

National Genetics Education and Family Support Center

Agenda

- Introduction to the Family Center
- Overview of Telegenetics
- Telewhat?! Infographic
- Other Telegenetics & Telehealth Resources
- What Families Need to Know: Provider Perspectives
- What Families Need to Know: Family Leaders' Perspective
- Questions

National Genetics Education and Family Support Center

National Genetics Education and Family Support Center (Family Center)

Made up of: Genetic Alliance, FAMILY VOICES®, Parent to Parent USA, P2P USA

Funded by HRSA to:

- Help families develop skills to partner with professionals and improve systems of care
- Assist RGNs in partnering with families & family-led orgs
- Assist with outreach to diverse & medically underserved families
- Provide Education & Support

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Overview of Telegenetics

What is Telegenetics?

- Appointment with a genetics healthcare provider using:
  - Computer
  - Phone
  - Tablet
- Takes place in:
  - Provider's office near you
  - Your Home
  - Other settings
- Four main types of Telegenetics appointments:
  - Video conferencing
  - Store and forward
  - Remote monitoring
  - Mobile health

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How Does a Live Video Conferencing Visit Work?

- 30 – 60 minute appointment
- Collect medical history and family history
- Local provider may help with a physical exam
- Recommendations for follow-up (e.g. genetic testing)

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Why is it Important?

- Improves access to genetic services
- Helps reduce the effects of common barriers such as
  - Distance
  - Time
  - Childcare
  - Mobility challenges
  - Transportation
- Provides significant benefits to families
  - Less distance
  - Less cost
  - Time savings
  - Increased # of available providers
  - More access to early detection
  - Increased patient satisfaction

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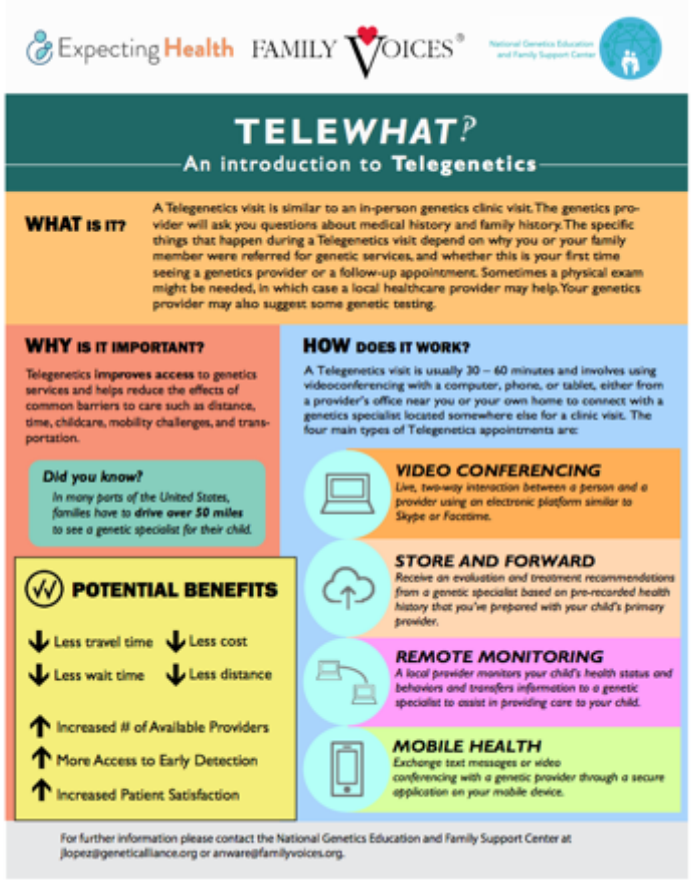
Telewhat?! Infographic

- Individuals and Families
  - Learn about Telegenetics
  - Prepare for a Telegenetics appointment
  - Share with other families

- Providers
  - Share with Telegenetics patients
  - Share with other providers

- Advocacy and Support Organizations
  - Disseminate the infographic to families
  - Share the infographic on social media
  - Upload the infographic to your website



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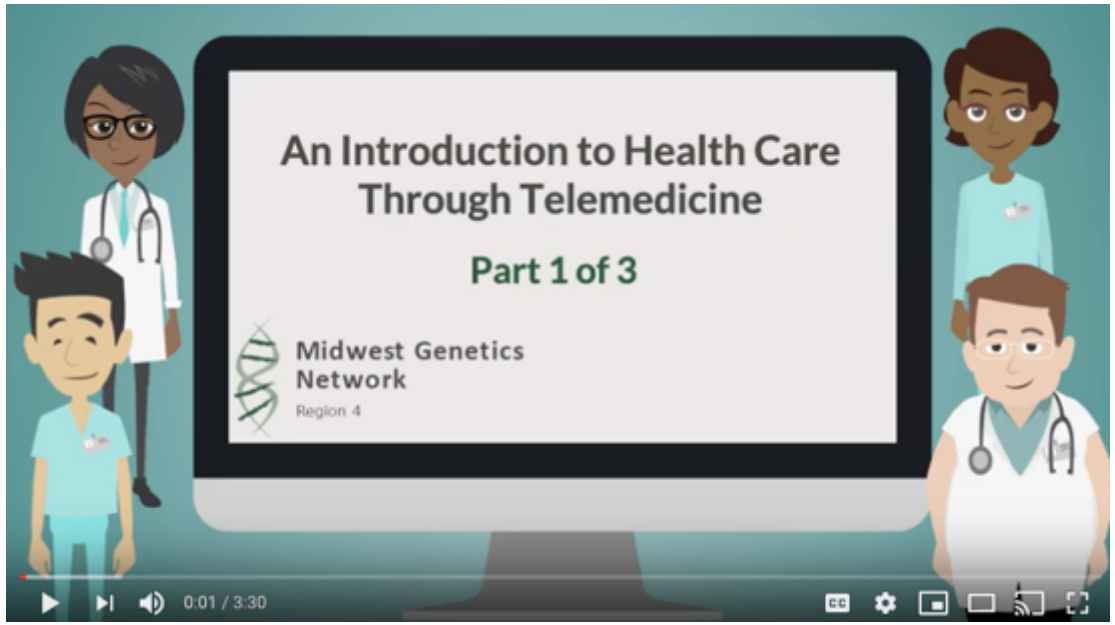
Additional Telehealth & Telegenetics Resources for Families and Providers

Midwest Genetics Network: Family Video Series



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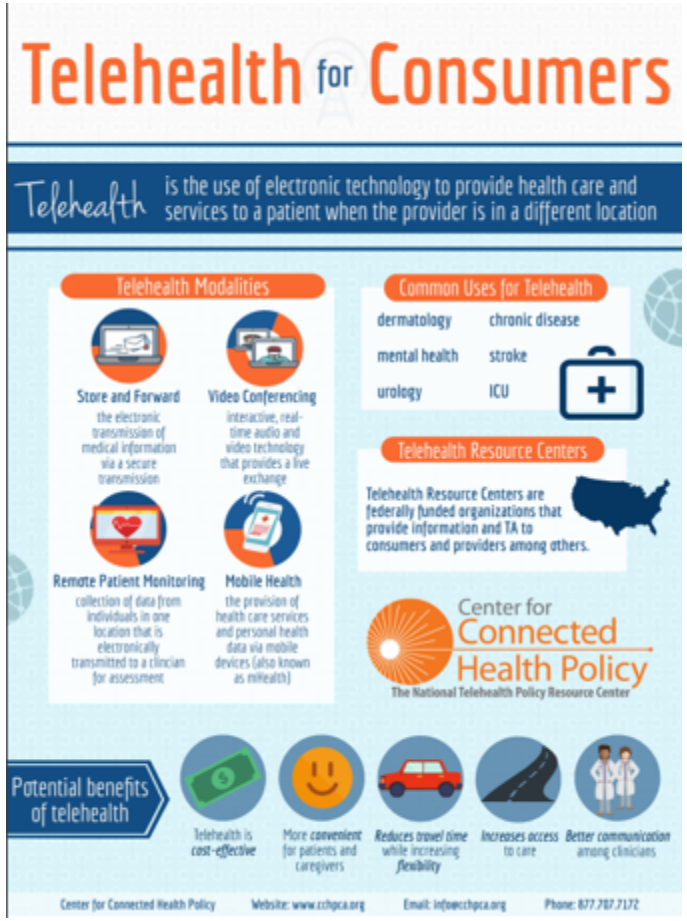
Western States Regional Genetics Network: Family Video

National Genetics Education and Family Support Center

Center for Connected Health Policy: Telehealth for Consumers Infographic



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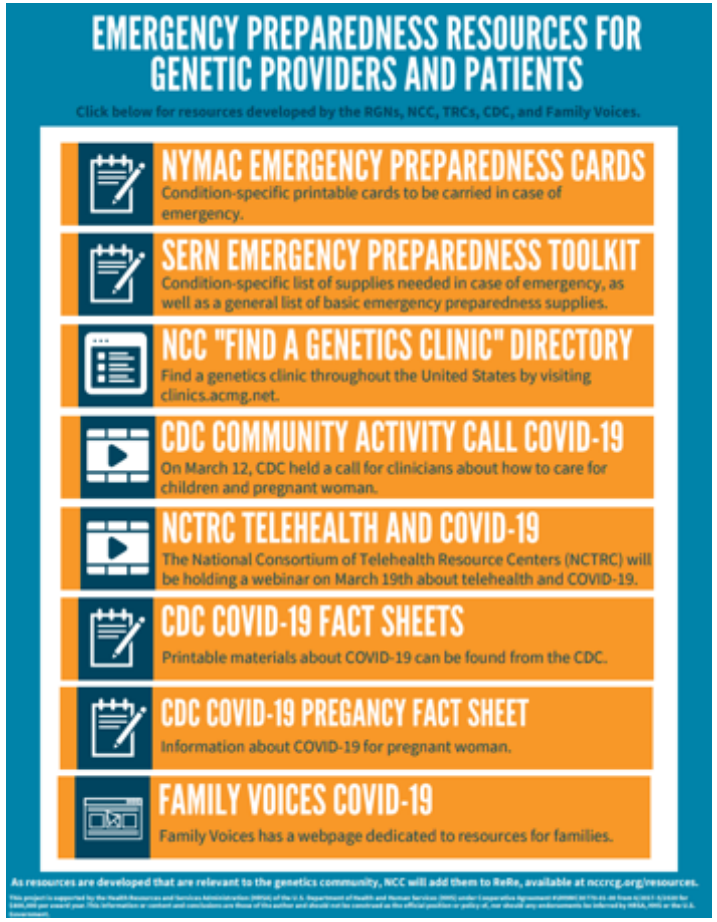
COVID-19 Resources



EMERGENCY PREPAREDNESS RESOURCES FOR GENETIC PROVIDERS AND PATIENTS

Click below for resources developed by the RGNs, NCC, TRCs, CDC, and Family Voices.

NYMAC EMERGENCY PREPAREDNESS CARDS
Condition-specific printable cards to be carried in case of emergency.

SERN EMERGENCY PREPAREDNESS TOOLKIT
Condition-specific list of supplies needed in case of emergency, as well as a general list of basic emergency preparedness supplies.

NCC "FIND A GENETICS CLINIC" DIRECTORY
Find a genetics clinic throughout the United States by visiting clinics.acmg.net.

CDC COMMUNITY ACTIVITY CALL COVID-19
On March 12, CDC held a call for clinicians about how to care for children and pregnant woman.

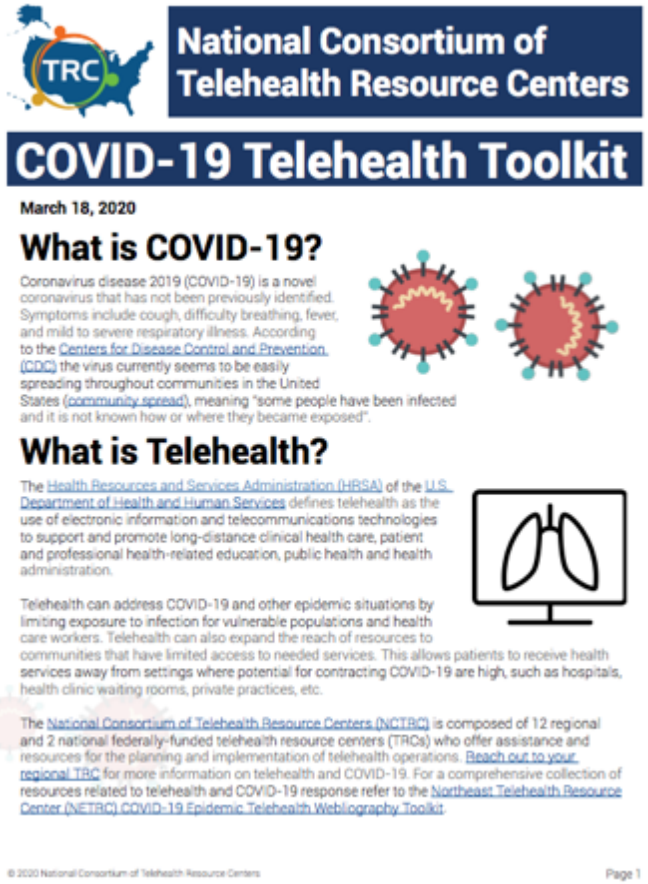
NCTRC TELEHEALTH AND COVID-19
The National Consortium of Telehealth Resource Centers (NCTRC) will be holding a webinar on March 19th about telehealth and COVID-19.

CDC COVID-19 FACT SHEETS
Printable materials about COVID-19 can be found from the CDC.

CDC COVID-19 PREGANCY FACT SHEET
Information about COVID-19 for pregnant woman.

FAMILY VOICES COVID-19
Family Voices has a webpage dedicated to resources for families.

As resources are developed that are relevant to the genetics community, NCC will add them to ReRe, available at nccrcg.org/resources.



National Consortium of Telehealth Resource Centers

COVID-19 Telehealth Toolkit

March 18, 2020

What is COVID-19?

Coronavirus disease 2019 (COVID-19) is a novel coronavirus that has not been previously identified. Symptoms include cough, difficulty breathing, fever, and mild to severe respiratory illness. According to the Centers for Disease Control and Prevention (CDC) the virus currently seems to be easily spreading throughout communities in the United States (community spread), meaning "some people have been infected and it is not known how or where they became exposed".

What is Telehealth?

The Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services defines telehealth as the use of electronic information and telecommunications technologies to support and promote long-distance clinical health care, patient and professional health-related education, public health and health administration.

Telehealth can address COVID-19 and other epidemic situations by limiting exposure to infection for vulnerable populations and health care workers. Telehealth can also expand the reach of resources to communities that have limited access to needed services. This allows patients to receive health services away from settings where potential for contracting COVID-19 are high, such as hospitals, health clinic waiting rooms, private practices, etc.

The National Consortium of Telehealth Resource Centers (NCTRC) is composed of 12 regional and 2 national federally-funded telehealth resource centers (TRCs) who offer assistance and resources for the planning and implementation of telehealth operations. Reach out to your regional TRC for more information on telehealth and COVID-19. For a comprehensive collection of resources related to telehealth and COVID-19 response refer to the Northeast Telehealth Resource Center (NETRC) COVID-19 Epidemic Telehealth Webliography Toolkit.

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Regional Genetics Networks: COVID-19 Resources

SRGN
Western States Regional Genetics Network

TELEHEALTH RESOURCES

This is a curated list of telehealth resources to get providers up and running with telehealth. Due to the COVID-19 crisis, we have included telehealth resources specifically for COVID-19, as well as, regular telehealth resources.

We will continue to update the page as we get new information.

- General Telehealth Implementation Resources
- Best Practices for Telehealth Providers
- Telehealth Resources for Patients
- Telegenetics Implementation

Telehealth Resources for COVID-19

Telehealth policies are rapidly changing to support activities in response to COVID-19. You may want to sign up to get notices from the HRSA funded Center for Connected Health Policy.

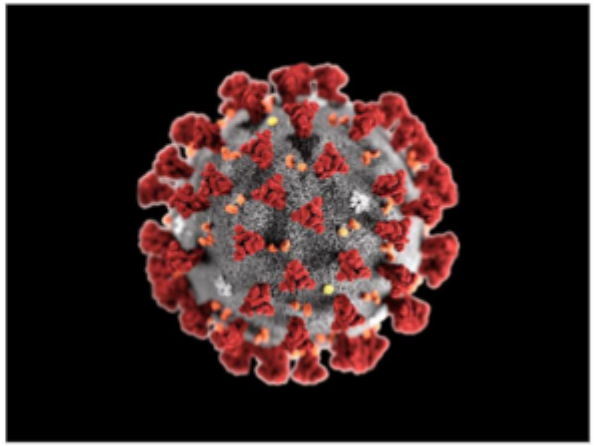
Mountain States
REGIONAL GENETICS NETWORK

Telemedicine and Telehealth Resources for COVID 19

March 25, 2020

With the current pandemic involving the coronavirus, COVID19 , many specialty and primary care providers are transitioning rapidly to utilizing telehealth modalities. We have gathered some of the resources that are available to help medical practices find the information and guidance they need to meet the ever-changing needs of their patients during this time.

If you are just beginning telehealth implementation, one of the best resources is to reach out to the Telehealth Resources Center (TRC) that your state belongs to. Unsure which TRC services you, click here to access their clickable map and connect directly to the one for your state.



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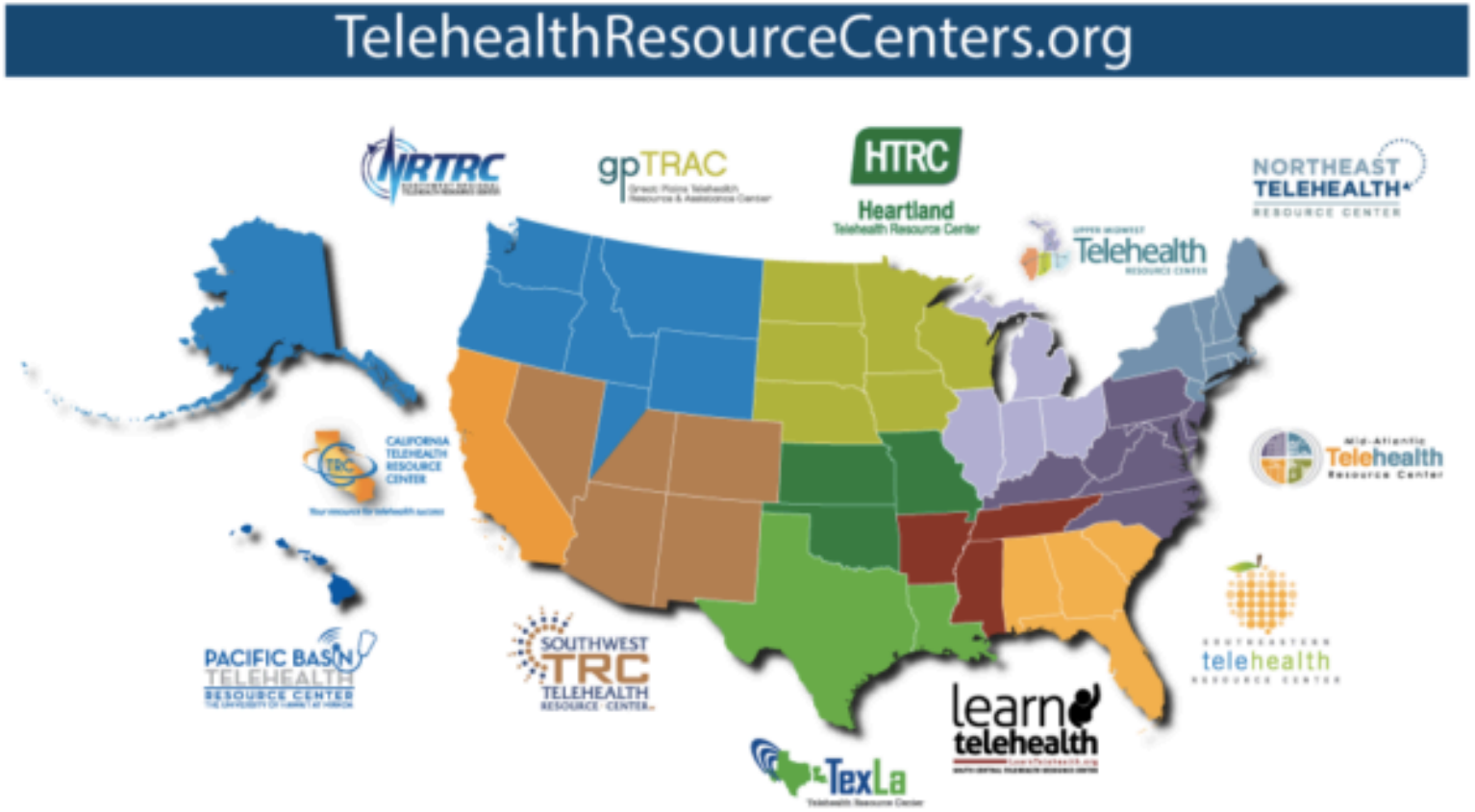
National Consortium of Telehealth Resource Centers (NCTRC)



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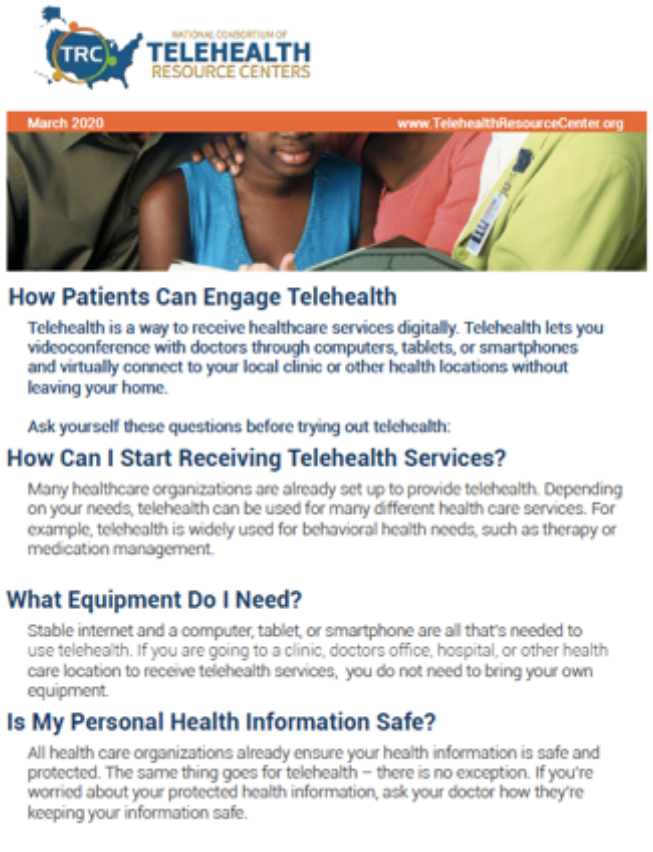
NCTRC: How Patients Can Engage Telehealth



NATIONAL CONSORTIUM OF TELEHEALTH RESOURCE CENTERS

March 2020 www.TelehealthResourceCenter.org

How Patients Can Engage Telehealth

Telehealth is a way to receive healthcare services digitally. Telehealth lets you videoconference with doctors through computers, tablets, or smartphones and virtually connect to your local clinic or other health locations without leaving your home.

Ask yourself these questions before trying out telehealth:

How Can I Start Receiving Telehealth Services?

Many healthcare organizations are already set up to provide telehealth. Depending on your needs, telehealth can be used for many different health care services. For example, telehealth is widely used for behavioral health needs, such as therapy or medication management.

What Equipment Do I Need?

Stable internet and a computer, tablet, or smartphone are all that's needed to use telehealth. If you are going to a clinic, doctors office, hospital, or other health care location to receive telehealth services, you do not need to bring your own equipment.

Is My Personal Health Information Safe?

All health care organizations already ensure your health information is safe and protected. The same thing goes for telehealth – there is no exception. If you're worried about your protected health information, ask your doctor how they're keeping your information safe.

NATIONAL CONSORTIUM OF TELEHEALTH RESOURCE CENTERS

March 2020 www.TelehealthResourceCenter.org

Can I Trust the Telehealth Doctor?

Meeting a new doctor can be nerve-wracking. States make it easy to find a doctor's education and credentials online. You can find out if your doctor has a medical license through your state's professional licensing board. Without a license, the doctor is not allowed to practice medicine.

This information is easily found through the Federation of State Professional Boards' website: https://www.fsmb.org/contact-a-state-medical-board.

Learn more about telehealth at www.telehealthresourcecenter.org.

This fact sheet was made possible by the 14 Telehealth Resource Centers and administered through grant #G22RH30356 from the Office for the Advancement of Telehealth, Federal Office of Rural Health Policy, Health Resources and Services Administration, Department of Health and Human Services.

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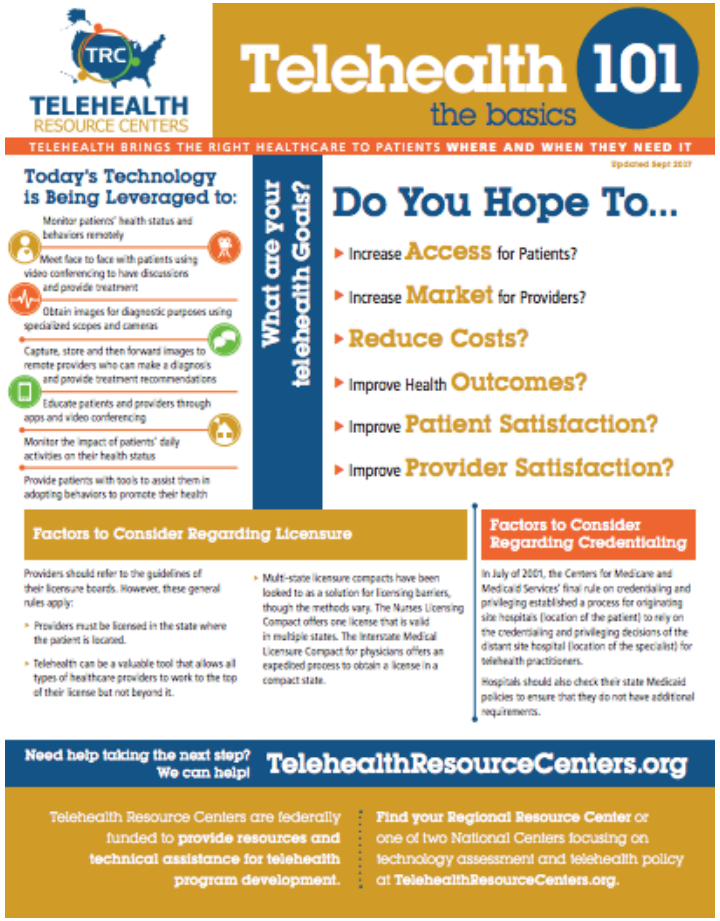
NCTRC: Telehealth 101 Infographic



TELEHEALTH RESOURCE CENTERS

Telehealth 101 the basics

TELEHEALTH BRINGS THE RIGHT HEALTHCARE TO PATIENTS WHERE AND WHEN THEY NEED IT

Updated Sept 2017

Today's Technology is Being Leveraged to:

- Monitor patients' health status and behaviors remotely
- Meet face to face with patients using video conferencing to have discussions and provide treatment
- Obtain images for diagnostic purposes using specialized scopes and cameras
- Capture, store and then forward images to remote providers who can make a diagnosis and provide treatment recommendations
- Educate patients and providers through apps and video conferencing
- Monitor the impact of patients' daily activities on their health status
- Provide patients with tools to assist them in adopting behaviors to promote their health

What are your telehealth Goals?

Do You Hope To...

- Increase **Access** for Patients?
- Increase **Market** for Providers?
- **Reduce Costs?**
- Improve Health **Outcomes?**
- Improve **Patient Satisfaction?**
- Improve **Provider Satisfaction?**

Factors to Consider Regarding Licensure

Providers should refer to the guidelines of their licensure boards. However, these general rules apply:

- Providers must be licensed in the state where the patient is located.
- Telehealth can be a valuable tool that allows all types of healthcare providers to work to the top of their license but not beyond it.
- Multi-state licensure compacts have been looked to as a solution for licensing barriers, though the methods vary. The Nurses Licensing Compact offers one license that is valid in multiple states. The Interstate Medical Licensure Compact for physicians offers an expedited process to obtain a license in a compact state.

Factors to Consider Regarding Credentialing

In July of 2001, the Centers for Medicare and Medicaid Services' final rule on credentialing and privileging established a process for originating site hospitals (location of the patient) to rely on the credentialing and privileging decisions of the distant site hospital (location of the specialist) for telehealth practitioners.

Hospitals should also check their state Medicaid policies to ensure that they do not have additional requirements.

Need help taking the next step? We can help! **TelehealthResourceCenters.org**

Telehealth Resource Centers are federally funded to **provide resources and technical assistance for telehealth program development.**

Find your Regional Resource Center or one of two National Centers focusing on technology assessment and telehealth policy at **TelehealthResourceCenters.org.**

Reimbursement Buckets

Medicare

Medicare is a Federal program administered at the federal level. Medicare provides some reimbursement for telehealth services. The program has specific requirements in three major areas: physical location of the patient, clinical service being provided and the provider's credentials. CMS's publication, Telehealth Services, provides an excellent overview of related Medicare policies.

You can find out if your location meets the rural eligibility requirements using HRSA's Payment Eligibility Analyzer.

Medicaid

Medicaid is a Federal program that is administered at the state level. Some states have laws to dictate Medicaid telehealth reimbursement policies and some states do not. Medicaid reimbursement varies greatly among states.

For information about Medicaid policies in your state, contact your Regional Telehealth Resource Center or visit Cchpca.org.

Private Insurance

Like Medicaid, private insurance mandates are administered at the state level. Some states have laws to dictate telehealth reimbursement policies and some states do not. Private insurance reimbursement varies greatly among states.

For more information, contact your Regional Telehealth Resource Center or visit Cchpca.org.

Reducing your Upfront Expenses

Equipment Purchases

- Carefully match your selection to clinical needs
- Develop models built on low cost technology options when possible
- Look to grant opportunities to capitalize the investment (e.g. the RUS Distance Learning and Telemedicine grant program)

Administrative Costs

- Optimize use of available reimbursement for services
- Adopt solutions from business plans of efficient and effective programs
- Explore HRSA's grant opportunities for program development (ORHP Rural Health and OAT network development grants)

Connectivity Costs

- Check your eligibility to participate in Universal Service Administrative Company subsidies
- Explore possibilities of reduced rates through FCC Regional Pilot Projects and state-level Healthcare Connect Fund programs

Choosing Your Equipment and Vendor(s)

Organizations are integrating a variety of technologies into their telehealth programs, from off-the-shelf webcams/laptops, tablets, and smart phones, to specialized field kits, mobile carts, wall-mount stations, and kiosks. Many systems integrate peripheral devices, such as exam cameras, stethoscopes, otoscopes, dermatoscopes and more. Telehealth software continues to evolve rapidly, featuring cloud-based videoconferencing, workflow and practice management tools, and EHR integration. For tips on equipment selection, contact your regional Telehealth Resource Center or visit TelehealthTechnology.org.

Factors to Consider Regarding HIPAA/Privacy

The technology alone cannot make one HIPAA compliant. Human action is required in order to meet the necessary level of compliance that is required. HIPAA does not have specific requirements related to telehealth. Therefore, a telehealth provider must meet the same requirements of HIPAA as would be needed if the services were delivered in-person.

Additionally, states may have their own privacy and security laws with which providers must be familiar. HIPAA is a baseline to protecting health information and some states may actually have a higher bar a provider must meet in order to be compliant. States also may have specific internet vendor laws that may not be directed at health services, but nonetheless impact them because they are services sold via the Internet. If a provider is offering services in another state, it would be prudent to look into the state laws covering these areas.

Factors to Consider Regarding Prescribing

The Ryan Haight Act dictates how telehealth (telemedicine is the term used in the Act) may be used to prescribe controlled substances. The Act provides specific scenarios on how the interaction between patient and provider must take place.

States have control over how everything else is prescribed when telehealth is used and the policies vary across states. Some states have very specific rules for the use of telehealth in prescribing while others are more vague or silent. Some of the rules center on whether telehealth is adequate to establish a patient-provider relationship which, again, varies across the states.

For more information about state laws and regulations, contact your Regional Telehealth Resource Center or visit Cchpca.org.

Get this document as an interactive file (with live links) on our website—or use this QR code to link directly to the file.

The National Consortium of Telehealth Resource Centers (NCTRC) is an affiliation of 14 Telehealth Resource Centers funded individually through cooperative agreements from the Health Resources & Services Administration, Office for the Advancement of Telehealth. The goal of the NCTRC is to increase the consistency, efficiency, and impact of federally funded telehealth technical assistance services.

This fact sheet, originally developed by the Northeast Telehealth Resource Center, was made possible by the NCTRC and administered through grant #G22RH30365 from the Office for the Advancement of Telehealth, Federal Office of Rural Health Policy, Health Resources and Services Administration, Department of Health and Human Services.

This fact sheet is for educational purposes only and does not constitute legal advice.

National Genetics Education and Family Support Center

Family & Provider Perspectives on Telegenetics

What Families Need to Know: A Provider's Perspective

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Considerations for Underserved Populations

- Do the faces on your screen reflect the faces in your exam room?

How are things looking?

- Access to Wifi
- Who's getting the message

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How does it sound?

- Availability of interpreter services
- Hospital systems
- F2F network of Cultural Liaisons

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The Family Center Can Help!

- Triaging, responding to questions and requests for information
- Linking individuals and families to Regional Genetics Networks
  - Promoting partnership and collaboration
- Connecting individuals and families to family-led organizations
  - Parent to Parent
  - Family to Family Health Information Centers
- Sharing educational materials
  - Webinars
  - Infographics
  - Sites: DiseaseInfoSearch.org, GenesInLife.org and the Advocacy ATLAS

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Family Center Regional Guides:
Referral to Support and Partnering with Family-Led Organizations

REFERRAL TO SUPPORT AND PARTNERING WITH FAMILY-LED ORGANIZATIONS: A REFERENCE GUIDE

The National Genetics Education and Family Support Center (Genetics Education & Family Support Center) is a companion project to the Regional Genetics Networks (RGNs). RGNs link medically underserved populations to quality genetic services and provide resources to genetic service providers, Primary Care Physicians, public health officials, and families. In many cases though, linking isn't enough. Individuals and families need direct support and assistance.

The Genetics Education & Family Support Center works to:

1. Assist the RGNs in their efforts to develop meaningful partnerships with families and family-led organizations and reach medically underserved and diverse families.
2. Provide emotional, informational, and navigational support for individuals and families who have, or are at-risk of having a genetic condition;
3. Provide education and resources on genetic conditions;
4. Link individuals and families to services and supports, especially those families in underserved areas
5. Help families develop skills to partner with professionals and improve systems of care

The following family-led organizations can help families navigate the system of care system and connect families to the information, resource, and support services they may need. In addition, family-led organizations can partner with RGNs and other families to help build capacity for family leadership and engagement to improve genetic educational materials, services, and programs.

FAMILY-LED ORGANIZATIONS: MOUNTAIN STATES REGIONAL GENETICS NETWORK (MSRGN)

	F2F/SAO	P2P	FFCMH	PTI/CPRC
Arizona	Raising Special Kids 602- 242-4366 or 800-237-3007 http://www.raisingspecialkids.org/	Raising Special Kids 602- 242-4366 or 800-237-3007 http://www.raisingspecialkids.org/	Family Involvement Center 602-412-4095 http://www.familyinvolvementcenter.org/ (Link works, but must copy and paste into your browser)	Raising Special Kids 602- 242-4366 or 800-237-3007 http://www.raisingspecialkids.org/
Colorado	Family Voices Colorado 303-733-3000 or 800-881-8272 https://familyvoicesco.org/	Ability Connection Colorado 303.691.9339 Hispano 877-472-7201 http://www.abilityconnectioncolorado.org/p2p-co/	Colorado FFCMH 888-429-3369 http://www.coloradofederation.org/	PEAK Parent Center 719-531-9400 or 800-284-0251 719-531-9403 (TTY) www.peakparent.org
Montana	Parents, Let's Unite for Kids (PLUK) 800-222-7585 or 406-255-0540 http://www.pluk.org/	Parents, Let's Unite for Kids (PLUK) 800-222-7585 or 406-255-0540 http://www.pluk.org/	Family Support Network (406) 256-7783 http://mtfamilysupport.org	Parents, Let's Unite for Kids (PLUK) 800-222-7585 or 406-255-0540 http://www.pluk.org/
New Mexico	Parent Reaching Out 505-247-0192 or 800- 524-5176 http://parentsreachingout.org/ http://parentsreachingout.org/es/	Parent Reaching Out 505-247-0192 or 800- 524-5176 http://parentsreachingout.org/ http://parentsreachingout.org/es/		Parent Reaching Out 505-247-0192 or 800- 524-5176 http://parentsreachingout.org/education/ http://parentsreachingout.org/es/sped/

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Thank you!