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Improving Access to Genetic Services for Underserved Populations

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Mission

Funded by the Health Resources and Services Administration (HRSA), the Regional Genetics Networks (RGNs), the National Coordinating Center for the Regional Genetics Networks (NCC), and the National Genetics Education and Family Support Center (NGEFSC or Family Center) mission is to improve access to genetic services for underserved populations.

National Coordinating Center for the Regional Genetics Networks

Who Do We Reach?

Our system works with healthcare providers, as well as individuals/families who may have, or at risk for, genetic conditions. Through our evaluation efforts, the RGNs identify if a provider or individual/family comes from a Medically Underserved Area/Population (MUA/P).

MUA/P is defined by HRSA as an area that has “specific sub-groups of people living in a defined geographic area with a shortage of primary care health services. These groups may face economic, cultural, or linguistic barriers to health care”.

National Coordinating Center
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Measuring Who We Reach

nccrcg.org

Performance Measures of the RGNs, NCC, and NGEFSC

- PM 1A: Genetic Education & Training
- PM 1B: Social Media, Resources & Web Analytics
- PM 2: Individuals Connected to a Geneticist
- PM 3: Providers Trained in Telehealth Modalities
- PM 4: Clinic Sites that Use Telehealth for Genetics
- PM 5: Patients Receiving Genetic Services via Telehealth

National Coordinating Center for the Regional Genetics Networks

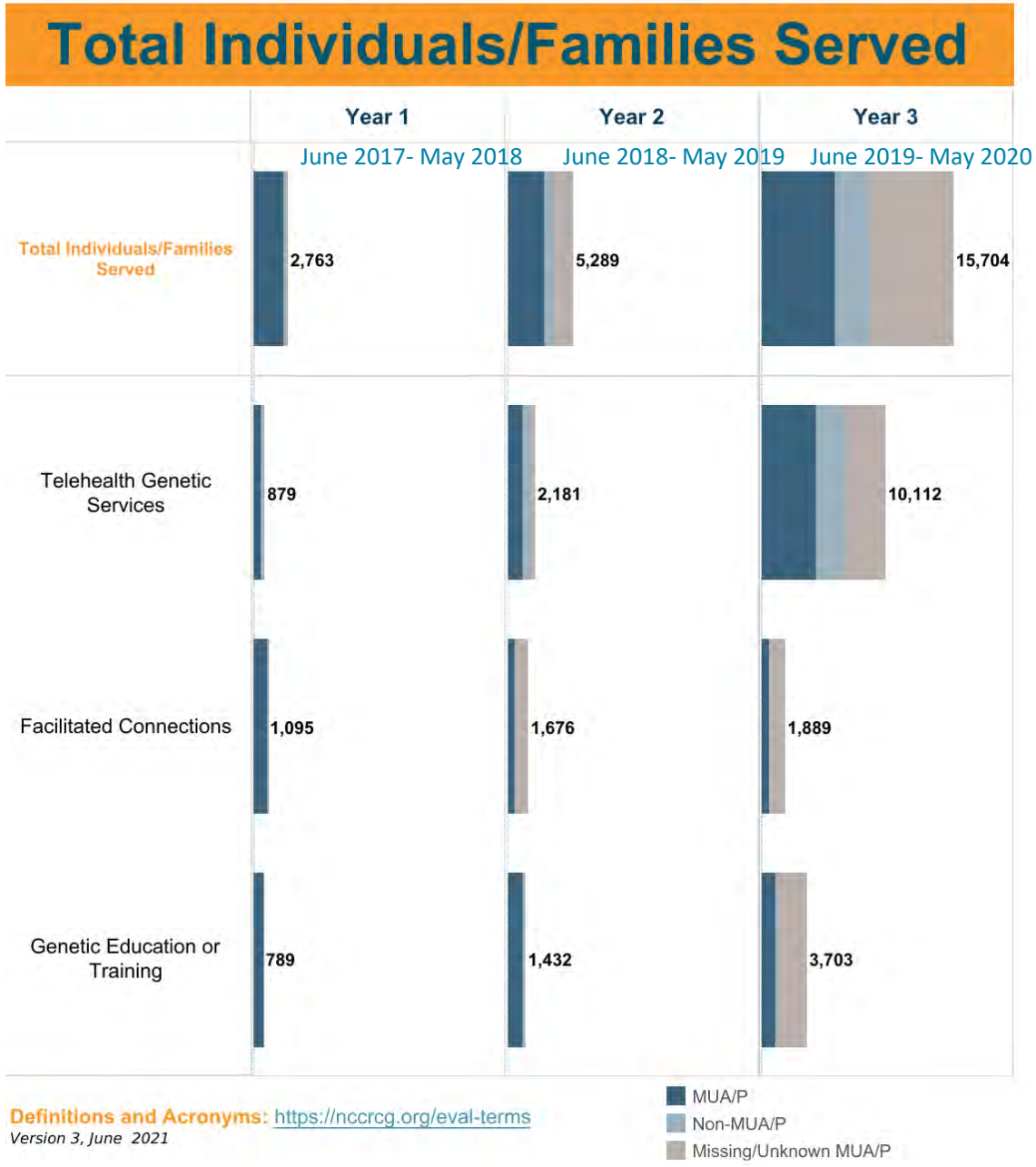
Who Do We Reach?

The current iteration of our system, including an updated evaluation mechanism, began in June 2017. From 2017 to 2020, the system progressively grew their reach through education and training.

National Coordinating Center for the Regional Genetics Networks

Who Do We Reach?

Similar to our engagement with providers, the system saw increased engagement of individuals/families through education and helping build connections between patients and genetics providers.



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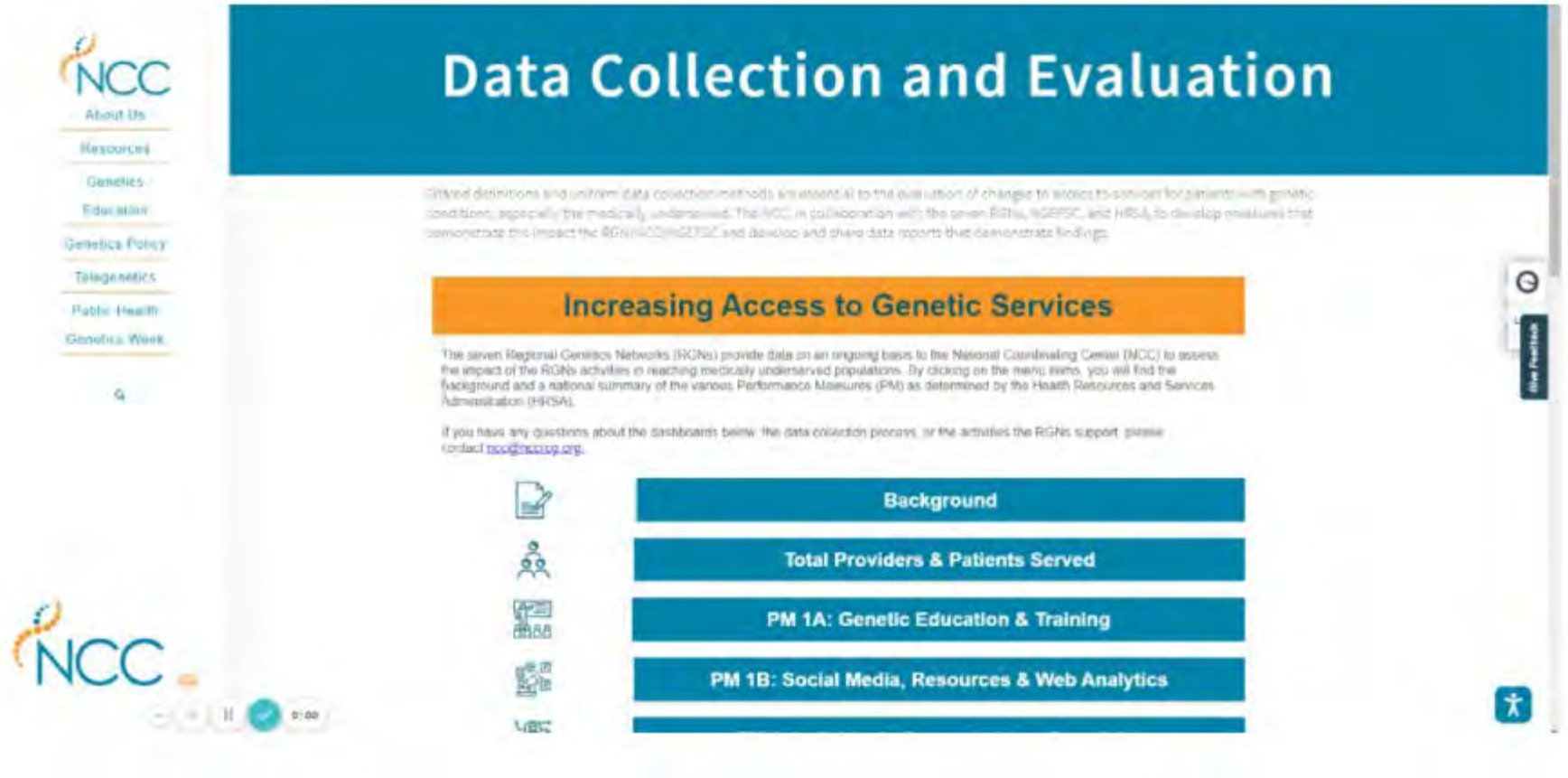
Who Do We Reach?

nccrcg.org/
evaluation



How does our system reach underserved populations?

Core Focus Areas

Genetics and Genomics Education

Telegenetics

Family Engagement and Partnership

Genetics Policy Education

Highlighted Resources from Our System

nergn NEW ENGLAND REGIONAL GENETICS NETWORK

Connecticut, Rhode Island, Massachusetts, New Hampshire, Maine, Vermont

Genetic Education Materials for School Success (GEMSS) provides a family-friendly starting point to help family members learn more about genetic conditions and offers ideas to encourage inclusion and participation in the classroom. GEMSS shares condition-specific information and resources for multiple audiences, including families, professionals, healthcare providers, and schools.

https://www.negenetics.org/genetic-education-materials-gemss

NYMAC regional genetics network

Delaware, District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, U.S. Virgin Islands, Virginia, West Virginia

NYMAC Telegenetics Navigation offers those interested in telegenetics, providing in-depth telegenetics program planning support. These services are open to genetics providers within the NYMAC region, as well as referring providers and patients.

https://nymacgenetics.org/providers/telemedicine-and-telegenetics/

SERN SOUTHEAST REGIONAL GENETICS NETWORK

Alabama, Georgia, Florida, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee

SERN's Emergency Preparedness Toolkit are disorder-specific lists of supplies needed in case of emergency, as well as a general list of basic emergency preparedness supplies. The toolkit is available in English, Spanish, and Dyslexic-friendly.

https://southeastgenetics.org/emergency-preparedness-toolkit/

Midwest Genetics Network
Region 4

Kentucky, Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin

Partnering with your Doctor: The Medical Home Approach is a guide to help families connect with their doctor, other medical professionals, and caregivers through a medical home. The guide is intended to be a user-friendly, hands-on tool to support families to move forward in obtaining and providing a medical home for their child. Available in English, Spanish, and Arabic.

https://midwestgenetics.org/resources/for-families/

HEARTLAND GENETICS SERVICES NETWORK

Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, South Dakota

Heartland works closely with the Marshallese population in their region to connect these individuals with genetic services. Through a strong collaboration with the community, Heartland holds genetic education events for the Marshallese population and has also developed resources to support the community. Resources include a newborn screening video in Marshallese.

https://www.youtube.com/watch?v=01b7EdE_SRM

Mountain States REGIONAL GENETICS NETWORK

Arizona, Colorado, Montana, New Mexico, Nevada, Texas, Utah, Wyoming

The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence. Each navigator receives training from MSRGN. Upon completion of this training, these 8 genetic navigators will be available by email to connect with families and assist them on their genetics journey.

https://www.mountainstatesgenetics.org/gn/

WSRGN Western States Regional Genetics Network

Alaska, California, Hawaii, Idaho, Oregon, Washington, Guam

WSRGN hosts a telegenetics training program. The training consists of self-paced on-line modules, webinars, and an one day in-person session. CMEs and CEUs are offered for the training. The training is done in partnership with the HRSA funded Southwest Telehealth Resource Center at the University of Arizona. Training sessions are held about once per quarter.

https://www.westernstatesgenetics.org/telegenetics/

National Genetics Education and Family Support Center

Disease InfoSearch is an online, information database for over 10,000 conditions that informs and supports individuals and family members affected by these conditions. The site provides disease descriptions, support organization listings and resources for additional information.

https://www.diseaseinfosearch.org

NCC National Coordinating Center for the Regional Genetics Networks

The Genetics Policy Hub, which will have a new website launched this fall, includes genetics policy education tools. Existing resources include: State Medicaid Genetics Policies Database, State/Federal Legislation/Regulation Tracking Map, Genetics Policy Hub Twitter, and more!

https://nccrcg.org/lift

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Resource Repository

nccrcg.org/
resources

May 23-27, 2022

Public Health Genetics Week

Public health genetics week seeks to raise awareness, and to celebrate, the field of public health genetics. Held during the last week of May, PHGW engages a variety of audiences to highlight the activities of public health genetics.

https://phgw.org

#PHGW
#PUBLICHEALTHGENETICS

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