EVALUATION METHODOLOGY

for the Regional Genetic Networks (RGNs), the National Coordinating Center (NCC), and the National Genetics Education and Family Support Center (NGEFSC) - the **RGN/NCC/NGEFSC system**.

Introduction

The RGN/NCC/NGEFSC system uses common Performance Measures (PMs) to provide national summary statistics about its activities for improving access to genetic services for underserved populations. The Health Resources and Services Administration (HRSA) Maternal and Child Health Branch (MCHB) Genetic Service Branch staff set forth five SMART Objectives in the RGN NOFO 20-046, which use the PMs to collect and report the data. Through the work of an NCC Data Collection and Evaluation Workgroup, programmatic activities information is collected nationally and then reported by NCC.

Data Methodology

The PMs were developed for the previous grant cycle (June 2017 to May 2020) and were refined for the current grant cycle (June 2020 to May 2024). Five years of data are displayed on this public-facing dashboard with our most recent set of complete statistics being from the grant year June 2021 to May 2022 (Year 5).

The seven RGNs, the NCC, and the Family Center collect data from a variety of sources (see word cloud for examples). Because of the diversity of activities that are designed to address regional needs, we developed shared definitions and instructions for ensuring consistent reporting by the nine organizations in the system.

NOFO Smart Objectives for the 2020-2024 Grant Cycle

1. By May 2024, each RGN will facilitate connections to genetic services for at least 2,000 individuals or families with or at risk for genetic conditions, within the geographic area served by the RGN.
2. By May 2024, increase to at least 33 percent of the individuals who are medically underserved with or at risk for genetic conditions, served by each RGN.
3. By May 2024, increase by 20 percent the number of health care providers receiving education or training through the RGN.
4. By May 2024, increase ~~by 20 percent~~** the number of individuals with or at risk for genetic conditions, receiving genetic services through telehealth visits.
5. By May 2024, increase by 20 percent the number of RGN resources accessed.

**The percent change and baseline will be established if and when there is a full year of data where telehealth visits are no longer significantly impacted by the current public health emergency well beyond the impact of the RGN program by May 2023. And if not, year 2 will be used as baseline.

Data Sources

Website Analytics
Social Media Analytics
Event Registration Excel AirTable
Survey monkey REDCap
Email
Surveys Qualtrics
Qualitative Approaches
Google Analytics

Core Definitions

A glossary of terms and definitions can be found at https://nccrcg.org/eval-terms/. Core terms include:

Medically Underserved

We utilize the HRSA definition of medically underserved (MUA/P) by collecting zip codes of system participants to identify if they come from Health Profession Shortage Areas (HPSAs). The NCC provides a MUAP ZIP Code Finder Tool in the NCC REDCap database.

Facilitated Connection

When RGN-supported activity demonstrates a direct connection to a patient receiving genetic healthcare services *or*
When services are provided through RGN-support to connect individuals/families to genetic services (healthcare or other support services relating to the patient's genetic conditions) outside of the healthcare system through a one-on-one communication.

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Data Collection and Visualization Methodology

The NCC hosts an aggregate database in REDCap. The database reflects the organization of data elements and the addition of new variables being collected for the PMs in Year Four. Qualitative information boxes were also added to capture the reasons for data changes in the four-year series, including new programs added or activities that have stopped.

The NCC utilizes Tableau for visualizations in this public-facing dashboard.

A Note About Counts

HRSA has asked the NCC/RGN/ NGEFSC system to capture the number of patients served. Therefore, these are counts of patients and participants, not activities.

Performance Measures of the RGN/NCC/NGEFSC System

Performance Measure 1A: Number of providers, individuals, and families that received education or training on genetics or genetic service delivery from the RGNs, NCC, or NGEFSC.

Performance Measure 1B: Number of resources on genetics developed by the RGN, NCC, or NGEFSC.

Performance Measure 2A: Number of patients for whom the RGN program facilitated new connections to genetic healthcare services provided within the healthcare system.

Performance Measure 2B: Number of individuals or families for whom the RGN program facilitated new connections outside of the healthcare system to genetic services.

Performance Measure 3: Number of providers trained or provided technical assistance through RGN-supported event that focuses on telehealth modalities for genetics.

Performance Measure 4: Number of RGN clinic sites that use telehealth modalities.

Performance Measure 5: Number of patients for whom telehealth modalities for genetics were used.

Learn more about the RGNs, NCC, and NGEFSC

Visit, nccrcg.org/regions, to find our interactive map to connect with your RGN!