Updates and Impact of the RGN/ NCC/ NGEFSC System from June 2017 - May 2023

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Updates and Future Direction of the NCC Products
National Coordinating Center for the Regional Genetics Networks

Funded by HRSA since 2004

Mission: Improve access to genetic services for underserved populations

Focus Areas

Education for non-genetics professionals and the general public

Genetics Policy Education for all genetic partners

Genetics Workforce assessments for genetics professionals

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Cooperative Agreement #UH9MC30770 from 6/2020 - 5/2024 for $800,000 per award year. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.
Select Outcomes from NCC

- 4 Supported Websites
- 1,200+ Healthcare Interpreters Trained
- 4 Training Programs
- 10 Languages for each training glossary
- 300+ Knowledge Nuggets started for CME
- 2,000+ PAs educated through educational modules
- 94 ACMG ACT Sheets and Algorithms updated 2022-2024
- 400+ Genetics legislation and regulation tracked
- 33 Genetics policy area primers available
- 150+ Attended one of four GPH webinars 2023-2024
Select Outcomes from NCC

800+ PHGW hashtag mentions

39 PHGW events

137 countries PHGW website visitors 2020-2023

1,275 Clinics in the ACMG “Find a Genetics Clinic” Directory

3,070 Respondents of the 2023 workforce survey, which included geneticists, genetic counselors, genetic nurses, genetic PAs, and metabolic dietitians
It will continue to be available through ACMG at clinics.acmg.net. Updates can be made directly on the website, and the Spanish version will be available shortly.
NCC hopes to have all Newborn Screening ACT Sheets completed by the end of funding.

Once NCC ends, ACMG will keep the ACT Sheets on their website.
The first manuscript from the 2023 survey is under review by HRSA.

NCC is currently working on the clinical and laboratory geneticists-specific manuscripts.
The fifth Public Health Genetics and Genomics Week will be held from May 20-24.

The goal of the week is to raise awareness, and celebrate the field of public health genetics and genomics.
Impact of the RGN/ NCC/ NGEFSC System from June 2017 - May 2023
**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.
To create a clear picture of the impact of the system, NCC publishes the annual Performance Measure data under three areas of impact.
68.5% (n=14,577) of providers who provided their zip code and participated in an education or training activity were identified as practicing in underserved areas from June 2017 to May 2023.
74.9% (n=5,022) of individuals/families who provided their zip code and participated in an education or training activity were from underserved areas from June 2017 to May 2023.
82.6% (n=4,730) of people who provided their zip code and were connected to genetic services were identified as coming from underserved areas from June 2017 to May 2023.
92.6% (n=1,370) of providers trained were genetics specialists from June 2017 to May 2023.
77.3% (n=576) of clinics supported were from an underserved area from June 2017 to May 2023.
54.7% (n=48,966) of telegenetics patients whose zip code was known were identified as coming from an underserved area from June 2017 to May 2023.