Regional Genetics Network Program
June 1, 2017-May 31, 2020 (3 YEARS)

Midwest Regional Genetics Network

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3-Prong Genetic Program

- Each of 7 Regional Genetics Network (RGN) will establish a network of partnerships and connections to link individuals and families to genetic services. RGNs must show that genetic services meet the needs of the populations being served, especially with a focus on medically underserved populations.

- The National Coordinating Center for the RGNs (NCC) serves as a national resource for a national infrastructure, genetics expertise and technical assistance (TA) to the regions, and addresses national issues related to genetics care service delivery systems. American College of Medical Genetics and Genomics.

- The National Genetics Education and Family Support Center serves as a national resource for patient engagement and patient-centered information that is culturally sensitive to diverse populations. Genetics Alliances, Inc.
7 Regional Genetics Networks (RGNs)


5. **Heartland**, University of Arkansas System: Arkansas, Iowa, Kansas, Missouri, Nebraska, Oklahoma, North Dakota, and South Dakota.


RGN Program Purpose

1. **ACCESS** - Link medically underserved populations (based on poverty, rural geographic location, and/or populations that experience health disparities)* to genetic services;

*Medically Underserved Areas/Populations are areas or populations designated by HRSA/HPSA as having too few primary care providers, high infant mortality, high poverty or a high elderly population. [http://www.hrsa.gov/shortage/find.html](http://www.hrsa.gov/shortage/find.html).

**HPSA – Health Professional Shortage Areas**

2. **QUALITY IMPROVEMENT** - Implement quality improvement activities to increase the connection with genetic services for the medically underserved.

3. **TELEGENETICS** - Implement evidence-based innovative models of telehealth and/or telemedicine with a focus on clinical genetics outreach.
RGN Program Requirements

1. Establish a **STEERING COMMITTEE** – to provide guidance on regional needs.

2. Create a **WEB-BASED RESOURCE** and **MAP** of genetic services and resources for genetic service providers, public health officials and families.

3. Establish **PARTNERSHIPS** (or contracts) with regional academic institutions, health systems or public health to coordinate and connect individuals and families to genetic services.

4. Connect with **STATES** and **COMMUNITY CENTERS** to identify and link underserved populations to genetic services.

5. Provide **TA** to primary care providers and other specialists on **INFORMATION TECHNOLOGY** outreach; and facilitate **TELEGENETICS** outreach services in the region.
RGN Program Requirements

6. Collaborate with the NCC:
   • Sharing information and products among the RGNs;
   • Quality Improvement activities;
   • Data evaluation and reporting;
   • Participate in NCC workgroups of interest to the region; and
   • Providing resources to genetic service providers, primary care, and public health agencies.

7. Collaborate with the Family Center:
   • Promote patient and family engagement in the RGN;
   • Outreach and referral for the medically underived;
   • Consumer and family leadership training in the genetics health care delivery system;
   • Education resources for patients; families providers and public health.
Individual Regional Projects

• Limited funding may be used for projects that address regional genetic service delivery issues

1. Long-Term Follow-up of individuals identified by newborn screening
2. Implementing new conditions on the Recommended Uniform Screening Panel (RUSP)
3. Transition from pediatrics to adult care
4. Access to a medical home

• SMART measures – specific, measurable, achievable, relevant, and time-bound)
Measuring RGN Success - Program Objectives

1. By May 2018, each RGN will provide services to at least 250 individuals or families within the geographic area served by the RGN.

2. By May 2020, each RGN will provide services to at least 1,500 individuals within the geographic area served by the RGN.

3. By May 2020, increase by 20 percent the number of medically underserved patients served by each RGN.

4. By May 2020, increase by 20 percent the percentage of clinical sites that use telehealth/telemedicine to provide genetic services.

5. By May 2020, increase by 20 percent the number of medically underserved patients receiving genetic services through telemedicine visits.

6. By May 2020, increase by 20 percent the number of primary care providers using RGN resources.

• Baseline data will be collected and provided to HRSA to establish the benchmark for the program objective by the end of YR 1.
Measuring RGN Success – Performance Measures (in progress)

1.a: Number of providers, individuals, and families that received education or training on genetics from the RGN program
1.b: Number of resources on genetics used/accessed from the RGN program
2. Number of patients for whom the RGN facilitated connections to a geneticist
3. Number of providers trained by the RGN in telehealth modalities for genetics
4. Number of RGN sites that use telehealth modalities
5. Number of patients for whom telehealth modalities were used for genetics
<table>
<thead>
<tr>
<th>HRSA #</th>
<th>PM #</th>
<th>Project</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>4</td>
<td>Telegenetics Mapping Project</td>
<td>Work with NCC to create/update map of genetics providers in NYMAC region</td>
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<tr>
<td>4</td>
<td>3,4</td>
<td>Telegenetics Navigator</td>
<td>NYMAC staff will provide assistance to programs seeking technical assistance related to telegenetics</td>
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<tr>
<td>4,5,6</td>
<td>3,4,</td>
<td>Telegenetics Community of Practice (TCOP)</td>
<td>Educational webinars and online discussion forum to support telegenetics practice.</td>
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<tr>
<td>1,2,4,5</td>
<td>3,4,5</td>
<td>Telegenetics Regional Center of Excellence</td>
<td>Funding to support expansion of telegenetics program and training of providers</td>
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RGN, MCHB Discretionary Grant Performance Measures (DGIS)

Core 1  Grant Impact  Form 1
Core 2  Quality Improvement  Form 2
Core 3  Health Equity - MCH Outcomes  Form 3
CB 3  Impact measurement  Form 4
CB 4  Sustainability  Form 5
CB 5  Scientific Publications  Form 6
CB 6  Products  Form 7

Additional Forms:
- Products, Publications and Submission Data Collection Form
- TA/Collaboration
<table>
<thead>
<tr>
<th>Core 2 Performance Measure</th>
<th>The percent of programs engaging in quality improvement and through what means, and related outcomes.</th>
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<tbody>
<tr>
<td>Goal: Quality Improvement</td>
<td>To measure quality improvement initiatives.</td>
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<tr>
<td>Level: Grantee</td>
<td>The percent of MCHB funded projects implementing quality improvement initiatives.</td>
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<td>Domain: Core</td>
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**GOAL**

**DEFINITION**

**Tier 1:** Are you implementing quality improvement (QI) initiatives in your program?
- Yes
- No

**Tier 2:** QI initiative:
What type of QI structure do you have? (Check all that apply)
- Team established within a division, office, department, etc. of an organization to improve a process, policy, program, etc.
- Team within and across an organization focused on organizational improvement
- Cross sectorial collaborative across multiple organizations

What types of aims are included in your QI initiative? (Check all that apply)
- Population health
- Improve service delivery (process or program)
- Improve client satisfaction/outcomes
- Improve work flow
- Policy improvement
- Reducing variation or errors

**Tier 3:** Implementation
Are QI goals directly aligned with organization’s strategic goals? Y/N
Has the QI team received training in QI? Y/N
Do you have metrics to track improvement? Y/N
Which methodology are you utilizing for quality improvement? (Check all that apply)
- Plan, Do, Study, Act Cycles
- Lean
- Six Sigma
- Other:

**Tier 4:** What are the related outcomes?
Is there data to support improvement in population health as a result of the QI activities? Y/N
Is there data to support organizational improvement as a result of QI activities? Y/N
Is there data to support improvement in cross sectorial collaboration as a result of QI activities? Y/N

**BENCHMARK DATA SOURCES**

N/A

**GRANTEE DATA SOURCES**

Grantee self-reported.

**SIGNIFICANCE**

-
Grants Management & Program Monitoring Activities

HRSA Kick-off call with each RGN Grantee on strategic program plan (DONE)

HRSA monthly calls with each RGN grantee team (TBD)
  1. Implementation of program
  2. Ongoing activities
  3. Budget balance

NCC workgroups and NCC/RGN/Family monthly calls
  1. RGN participation
  2. Attendee communication with key program staff

HRSA review of grantee products
  1. 10 days in advance of publication or public dissemination
  2. Includes manuscripts, surveys, poster presentation, etc.

Budget oversight - status of budget
  1. Scheduled meetings with grantee fiscal office
  2. Carryforward Request - timely
  3. No Cost Extension Request timely
Grants – Genetic Services Branch

Newborn Screening Program
• NBS Data Repository and Technical Assistance Center
• Newborn Screening Clearinghouse
• Newborn Screening and Quality Improvement Program
• Newborn Screening for Severe Combined Immunodeficiency (SCID)

Genetic Program
• Regional Genetics Networks
• National Coordinating Center for the Regional Genetics Networks
• National Genetics and Family Support Center

Advisory Committee on Heritable Disorders in Newborns and Children
Other Grants – Genetic Services Branch

Hemophilia Program
• Regional Hemophilia Networks
• National Hemophilia Program Coordinating Center

Sickle Cell Disease Program
• Sickle Cell Disease Newborn Screening Program
• Sickle Cell Disease Treatment Demonstration Program and a National Coordinating Center

Thalassemia Program

Maternal and Child Environmental Health (MCEH) Network
• MCEH Network
• MCEH CoIIN
Contact Information

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