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# MSRGN Measures, Data Collection, and Outcomes Reporting

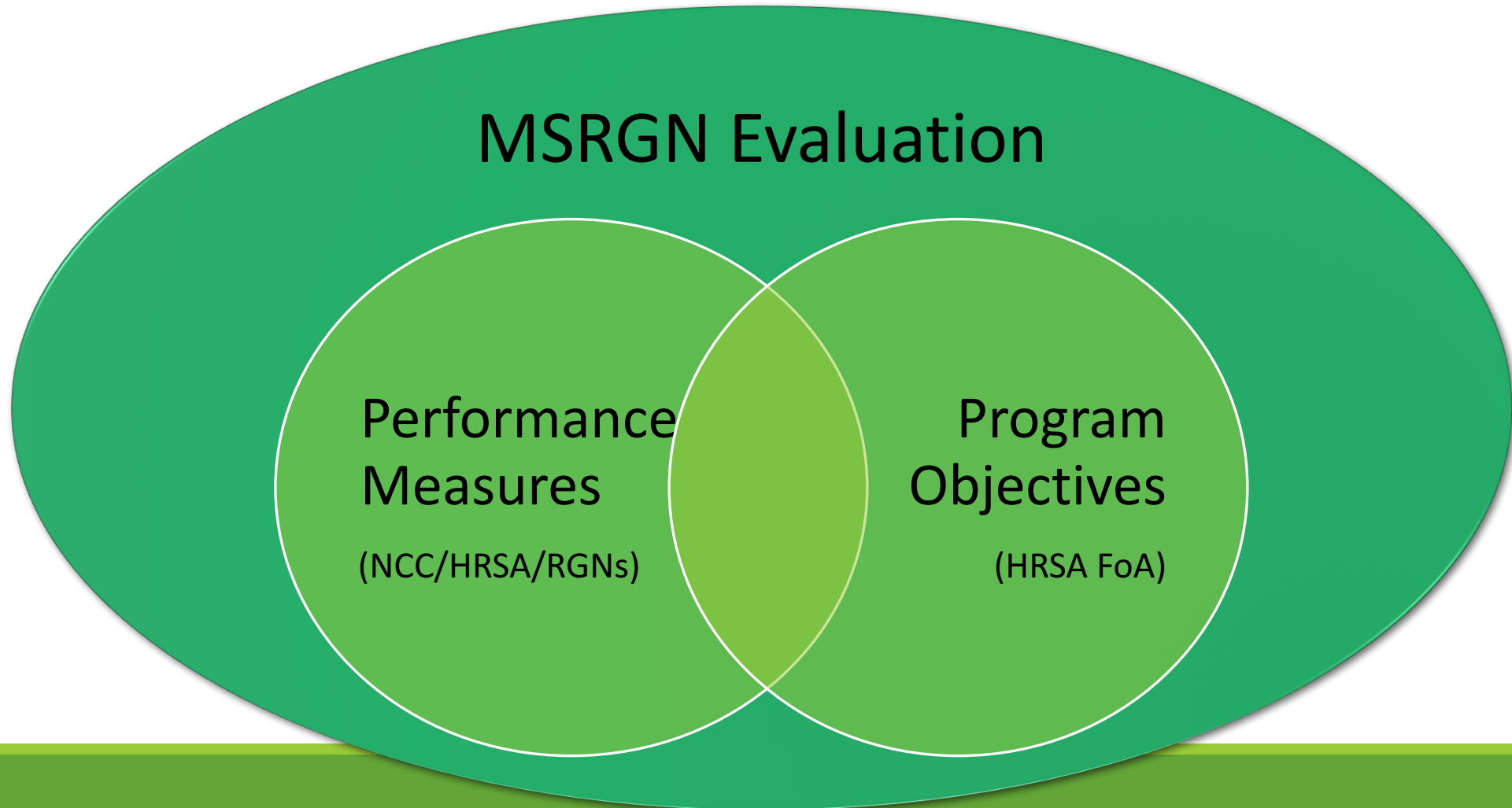
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MSRGN STATE TEAMS MEETING, JANUARY 10, 2018

AUSTIN, TEXAS

# MSRGN Evaluation

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# MSRGN Program Objectives

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Grant required program objectives:

- By May 2018, each RGN will provide services to at least 250 individuals or families within the geographic area served by the RGN.
- By May 2020, each RGN will provide services to at least 1,500 individuals within the geographic area served by the RGN.
- By May 2020, increase by 20 percent the number of medically underserved patients served by each RGN.
- By May 2020, increase by 20 percent the percentage of clinical sites that use telehealth/telemedicine to provide genetic services.
- By May 2020, increase by 20 percent the number of medically underserved patients receiving genetic services through telemedicine visits.
- By May 2020, increase by 20 percent the number of primary care providers using RGN resources.

# National Performance Measures

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As part of national evaluation (led by National Coordinating Center), all Networks measure and report:

- How many providers, individuals, and families are receiving education or are trained on genetics from the RGN program?
- How many providers, individuals, and families are receiving education or are trained on genetics from the RGN program?
- How many patients for whom the RGN program facilitated connections to a geneticist?
- How many providers are trained by the RGN in telehealth modalities for genetics?
- How many RGN sites are using telehealth modalities?
- How many patients for whom telehealth modalities for genetics were used?

# MSRGN Evaluation Overview

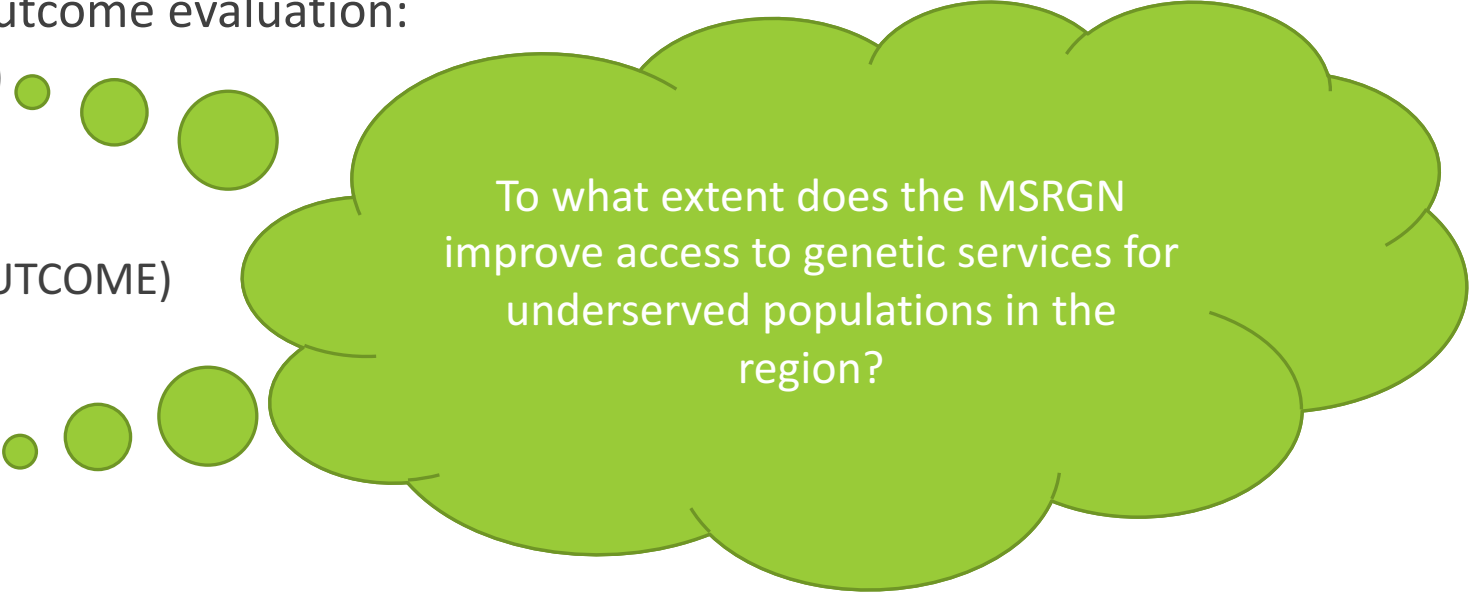
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Grant requires evaluation to determine:

- to what extent the program objectives have been met
- to what extent these outcomes can be attributed to the project

Responsible for both process and outcome evaluation:

- How much are we doing? (PROCESS)
- What difference are we making? (OUTCOME)



To what extent does the MSRGN  
improve access to genetic services for  
underserved populations in the  
region?

# Our Work So Far

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Crosswalk national and regional measures

Identify indicators and baseline time frame

Identify data sources for each process and outcome measure

Detail analytic plan

| Evaluation Question:<br>What difference are we making?                              | Indicator/Measure   | Data Source/Method   | Analysis  | Relationship to HRSA Program Objectives |
|---|---|--|---|---|
| How many patients for whom the RGN program facilitated connections to a geneticist? | Number of patients for whom the RGN program facilitated connections to a geneticist | Participating clinics (referrals and genetic appointments); GARD counts from region; pilot survey for parents/families | Number of patients for whom the RGN program facilitated connections to a geneticist; will also document annual trends | 1, 2, 3                                 |

# MSRGN Data Reporting

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- |   |   |
|---|---|
| 1) Number of individuals or families receiving services within each RGN <sup>9</sup>  | 6) Number of patients/families receiving education and resource materials                           |
| 2) Number of medically underserved patients receiving services within each RGN  | 7) Number of health care providers receiving education or using RGN resources                       |
| 3) Number of primary care, genetic service providers, and public health officials, participating in the regional network infrastructure | 8) Number of hits on RGN website and social media by stakeholders, providers and consumers          |
| 4) Number of technical assistance activities/services provided to genetic service providers   | 9) Number of clinical sites that use telehealth/telemedicine to provide genetic services            |
| 5) RGN participation in QI activities to connect the medically underserved to genetic services  | 10) Number of medically underserved patients receiving genetic services through telemedicine visits |

<sup>9</sup> An individual or family directly 'served' by the RGN is one for whom a genetic appointment has been facilitated through RGN resources, for example through a telehealth program, or indirectly through outreach and education to primary care or public health



# MSRGN Data Sources

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| Reporting Requirement   | Data Source(s):  |
|---|--|
| 1) Number of individuals or families receiving services within each RGN <sup>9</sup>  | Participating Clinics<br>State Teams (depending on state activities) and partners<br>Family Survey |
| 2) Number of medically underserved patients receiving services within each RGN  | Participating Clinics<br>State Teams (depending on state activities) and partners<br>Family Survey |
| 3) Number of primary care, genetic service providers, and public health officials, participating in the regional network infrastructure | MSRGN Documents (rosters, registration lists, etc)<br>Website and social media statistics          |
| 4) Number of technical assistance activities/services provided to genetic service providers   | MSRGN Documents  |
| 5) RGN participation in QI activities to connect the medically underserved to genetic services  | MSRGN Documents and associated data collection   |



# MSRGN Data Sources

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| Reporting Requirement   | Data Source(s):   |
|---|---|
| 6) Number of patients/families receiving education and resource materials                           | MSRGN Documents (rosters, registration lists, etc)<br>Website and social media statistics |
| 7) Number of health care providers receiving education or using RGN resources                       | MSRGN Documents (rosters, registration lists, etc)<br>Website and social media statistics |
| 8) Number of hits on RGN website and social media by stakeholders, providers and consumers          | Website and social media statistics   |
| 9) Number of clinical sites that use telehealth/telemedicine to provide genetic services            | Participating Clinics   |
| 10) Number of medically underserved patients receiving genetic services through telemedicine visits | Participating Clinics   |

# Additional MSRGN Measured Outcomes

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| Evaluation Question   | Data Source(s):                                 |
|---|---|
| To what extent are MSRGN stakeholders engaged in MSRGN activities and planning efforts?                                 | Stakeholder Surveys<br>Key Informant Interviews |
| To what extent are MSRGN stakeholders satisfied with the MSRGN?   | Stakeholder Surveys<br>Key Informant Interviews |
|   |   |
| To what extent is MSRGN improving health outcomes?<br>-specific outcome measure not yet defined                         | TBD   |
|   |   |
| To what extent are genetics clinics in the Mountain States Region serving patients residing in underserved communities? | Mapping project data<br>HPSA/zip code data      |

# Next Steps in Data Collection

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Finalize all evaluation crosswalks and outcome measures

Confirm all data sources

Finalize all data tracking forms/systems

Confirm all organizational data sharing requirements (in consultation with clinics/orgs)

Finalize and submit IRB protocol

Coordinate and implement Year 1 data collection

# Other Evaluation Activities

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Technical assistance to state or community-based organizations

- Evaluation planning
- Instrument development / identification
- Data analysis

Example: Wyoming Telegenetics Project

# Contact Information

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