



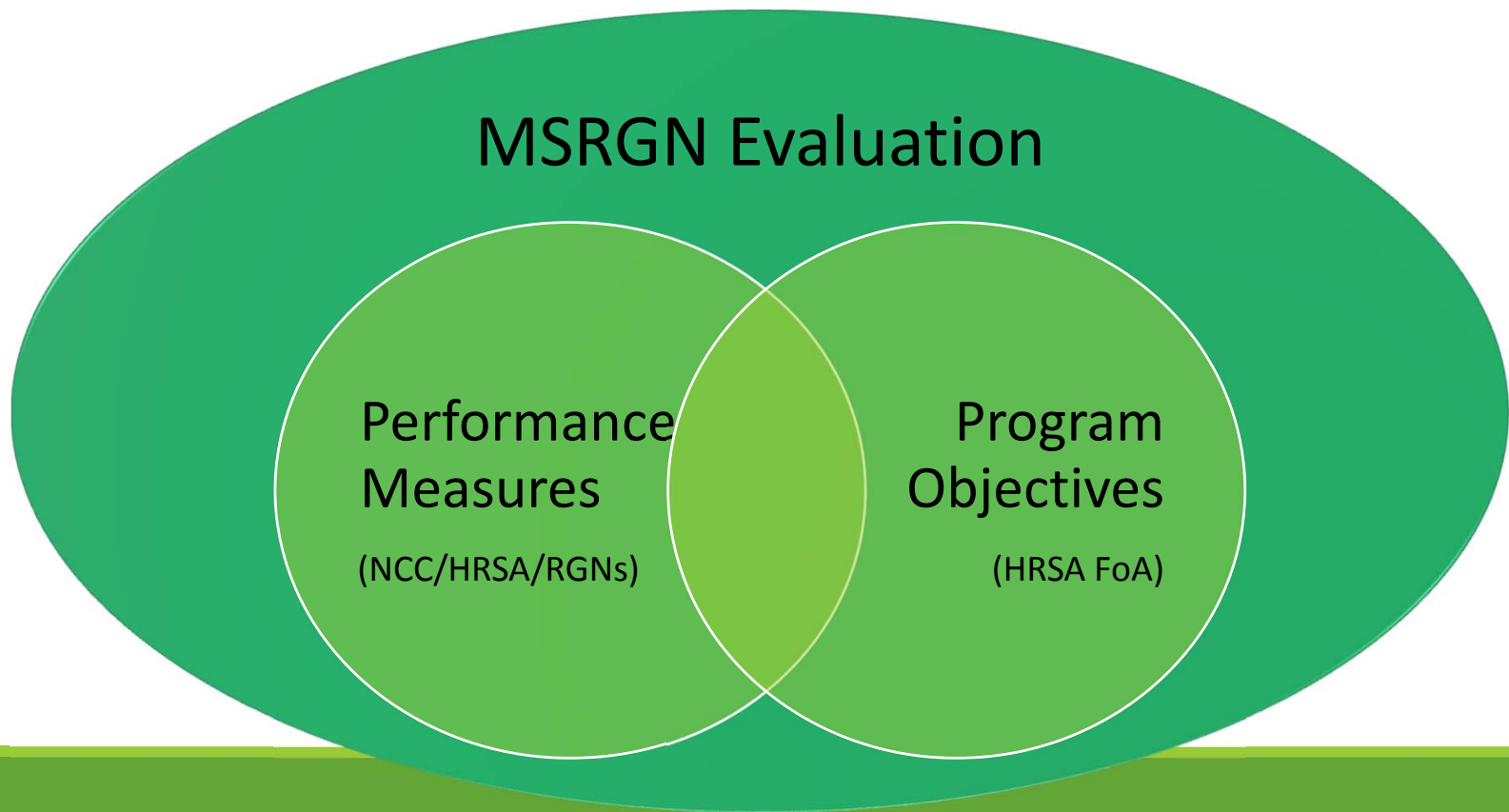
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MSRGN Measures, Data Collection, and Outcomes Reporting

MSRGN STATE TEAMS MEETING, FEBRUARY 15, 2019

AUSTIN, TEXAS

MSRGN Evaluation




HRSA Program Objectives

By May 2018:


- Serve at least 250 individuals or families.

By May 2020:

- Serve at least 1,500 individuals or families.
 - Increase by 20 percent the number of medically underserved patients served by each RGN.
 - Increase by 20 percent the percentage of clinical sites that use telehealth/telemedicine to provide genetic services.
 - Increase by 20 percent the number of medically underserved patients receiving genetic services through telemedicine visits.
 - Increase by 20 percent the number of primary care providers using RGN resources.
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HRSA National Performance Measures

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

- Number of providers, individuals, and families that received education or training on genetics from the RGN program
 - Number of resources on genetics used/accessed from the RGN program
 - Number of patients for whom the RGN program facilitated connections to a geneticist
 - Number of providers trained by the RGN in telehealth modalities for genetics
 - Number of RGN-supported sites that use telehealth modalities
 - Number of patients for whom telehealth modalities for genetics were used
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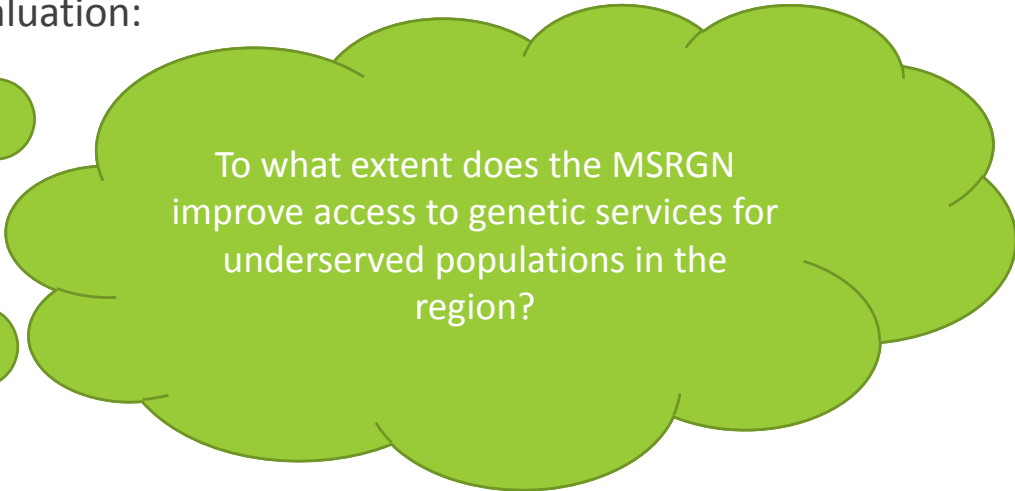
MSRGN Evaluation Overview

Cooperative Agreement 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

- Crosswalk national and regional measures
- Identify indicators and baseline time frame
- Identify data sources for each process and outcome measure
- Detailed analytic plan
- IRB submission and review
- Year 1 data submission to NCC data collection system
- Year 1 data included in performance report submitted to HRSA

Evaluation Question: 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

- 1) Number of individuals or families receiving services within each RGN⁹
- 2) Number of medically underserved patients receiving services within each RGN
- 3) Number of primary care, genetic service providers, and public health officials, participating in the regional network infrastructure
- 4) Number of technical assistance activities/services provided to genetic service providers
- 5) RGN participation in QI activities to connect the medically underserved to genetic services
- 6) Number of patients/families receiving education and resource materials
- 7) Number of health care providers receiving education or using RGN resources
- 8) Number of hits on RGN website and social media by stakeholders, providers and consumers
- 9) Number of clinical sites that use telehealth/telemedicine to provide genetic services
- 10) Number of medically underserved patients receiving genetic services through telemedicine visits

⁹ 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

Reporting Requirement	Data Source(s):
1) Number of individuals or families served by each RGN ⁹	Participating Clinics (telegenetics, primary care, etc) State Teams (depending on state activities) and partners MSRGN educational/training records
2) Number of medically underserved patients served by each RGN	Participating Clinics (telegenetics, primary care, etc) State Teams (depending on state activities) and partners MSRGN educational/training records
3) Number of primary care, genetic service providers, and public health officials, participating in the regional network infrastructure	MSRGN Documents (rosters, registration lists, etc) 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

⁹ 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

Reporting Requirement	Data Source(s):
6) Number of patients/families receiving education and resource materials	MSRGN Documents (rosters, registration lists, etc) Website and social media statistics
7) Number of health care providers receiving education or using RGN resources	MSRGN Documents (rosters, registration lists, etc) 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 MSRGN Surveys
10) Number of medically underserved patients receiving genetic services through telemedicine visits	Participating Clinics MSRGN Surveys

Additional MSRGN Measured Outcomes

Evaluation Question	Data Source(s):
To what extent are MSRGN stakeholders engaged in MSRGN activities and planning efforts?	Stakeholder Survey, Year 3
To what extent are MSRGN stakeholders satisfied with the MSRGN?	Stakeholder Survey, Year 3
To what extent is MSRGN improving health outcomes?	TBD (potentially National Survey of Children's Health)
To what extent are genetics clinics in the Mountain States Region serving patients residing in underserved communities?	Mapping project data HPSA/zip code data from participating clinics/providers

Year 1 Summary

Performance Measure	# of Interactions with Individuals/Families	# of Interactions with Providers	Other
PM 1a - Education and Training	34	97	
PM 1b - Website & Social Media	Details on next slide		
PM 2 - Facilitated Connections	16*		
PM 3 - # of Providers Trained, Telegenetics		1	
PM 4 - # of RGN sites using Telehealth			5 (distant) 17 (originating)
PM 5 - # of patients seen with Telehealth	90		

*Includes only in-person genetics visits referrals in state team projects

**Includes all reported telegenetics visits in RGN-supported telegenetics programs

Website and Social Media Statistics, Y1

State	Primary Users (unique users)	Primary Visits (non-unique user visits)
Arizona	73	98
Colorado	142	194
Montana	22	38
Nevada	24	54
New Mexico	38	56
Texas	353	590
Utah	34	44
Wyoming	13	21
Combined non-MSRGN States	583	1,138
Total:	1,282	2,233

OTHER RELATED STATS:

Resources Downloaded/Accessed: 235

- Total downloads: 830

Facebook Followers: 656

Facebook Reach: 44,943

Facebook Engagement: 2,587

Facebook Impressions: 79,632

PMs and the Program Objectives, Y1

	Duplicated count	Unduplicated count
PM 1a (education/training for indiv/families only)	34	23 (81% underserved)
PM 2 (facilitated connections)	106*	16** (69% underserved)
PM 5 (telegenetics visits)	90	90 (63% underserved)
TOTALS:	233	129 (72% underserved)

* Includes telegenetics visits

**Does not include telegenetics visits

Looking Forward to Year 2

Continue data collection

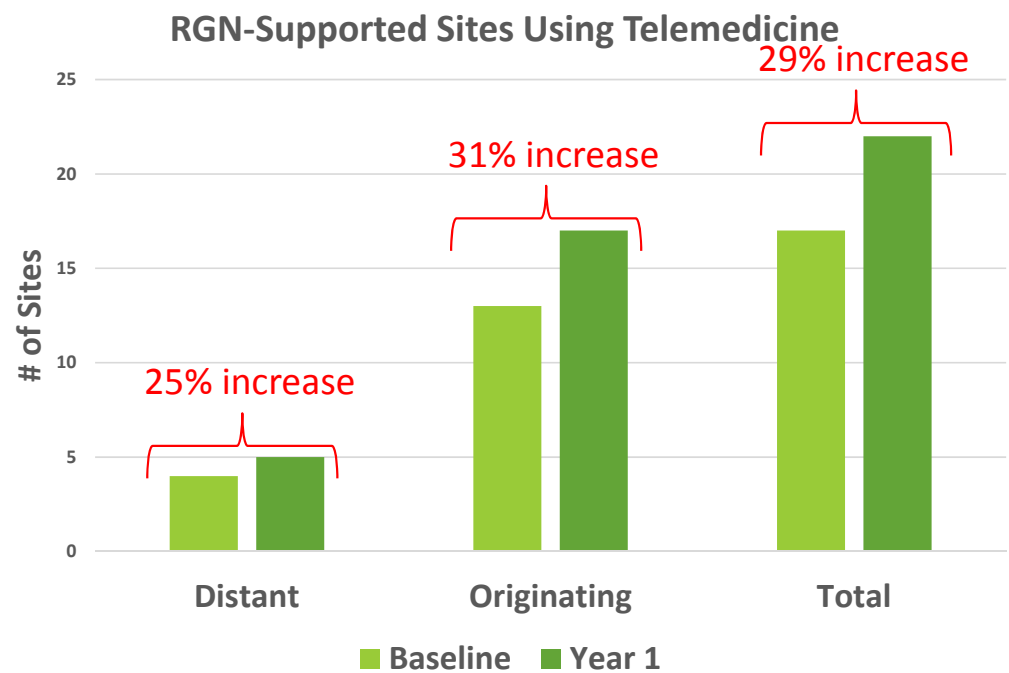
- Existing clinics/providers
- New clinics/providers (primary care offices)
- Genetics Summit data
- Other educational/training activity data
 - Facebook Live
 - Metabolic University
- State team projects

Data submission to NCC – Summer 2019

- REDCap submission system will open soon

Begin trend (% change) analysis

- Example



National Data Reporting

NCC coordination of regional comparisons and reporting aggregate data nationally

Why have a national-level view of all RGN activities?

- Reporting to HRSA the results of the national system
- Consistent metrics across regions
- Increased sample size
- Adds value to policy and decision making conversations



Challenges


- Unit of analysis (individual vs. aggregate)
- Measurement inconsistencies
- Different regional activities and approaches
 - Resulting in (potentially) large regional variation

Possible solutions?

Adding context (qualitative data)
Describing data in multiple ways
Considering sophisticated w/in region analyses to highlight changes (e.g. comparing intervention vs. non-intervention site data)

Other Regional Evaluation Activities

Technical assistance to state teams or community-based organizations

- Evaluation planning
 - Instrument development / identification
 - Data analysis
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Questions?

Liza M. Creel, PhD, MPH
Assistant Professor, Health Management & Systems Sciences
Commonwealth Scholar, Commonwealth Institute of Kentucky
School of Public Health & Information Sciences
University of Louisville
485 E. Gray Street
Louisville, KY 40202
Email: liza.creel@louisville.edu
Phone: 502-852-3283

Deborah Niyongabo, MPH
Graduate Research Assistant
Health Management & Systems Sciences
School of Public Health & Information Sciences
University of Louisville

