

Regional Genetics Networks

Performance Measures Detail Sheet Final

(1/9/18)

Updated based on HRSA Data Refinements (June 27, 2019)

Overall cross-activity reporting

RGNs should report activities in one performance measure and be consistent over the three-year funding cycle (6/1/17-5/31/20) in their year-to-year counts.

HRSA will have discussions with the RGNs about which activities should be included/excluded in the performance measures. Some activities may be more appropriately captured in individual RGN progress reports.

What is the baseline year?

The numbers collected in the first year of this grant cycle (2017-2020) for all measures (except measure 4, see below) will become the year 1 baseline. In years 2 and 3, percent change from the first year will be calculated to meet the FOA reporting requirements.

- For measure 4 (telehealth sites), RGNs should use the baseline they collected in the previous grant cycle for the universe of sites doing telegenetics, regardless of service type and whether the RGN (or RC) supported the activity. If RGNs already have this data on the universe, they report that at the beginning of this grant cycle. If a region does not have a baseline on the universe of existing telegenetics sites, HRSA expects the RGN to collect this data to establish a baseline in the first year. Therefore, the baseline data dates will vary among the RGNs for the denominator establishment. For reporting, HRSA-funded sites are reported in the context of the universe of telehealth sites. Year-to-year percent changes are calculated not on the universe of sites, but on the increases that result from HRSA funding.
 - E.g., 100 telegenetics sites, from before/first year, RGN supports 5, the % change is based on this number (5) of RGN-supported sites.

What variables are required vs. optional?

Yellow highlights are required data in each performance measure and are considered essential to the FOA reporting requirements. The other information (e.g., the variables in the notes and stratifiers) will be variables in the NCC REDCap and collected at the discretion of each RGN.

How will medically underserved be defined?

All RGNs are required to collect zip codes for providers and individuals/families to demonstrate service delivery to the medically underserved (exceptions will be noted in each performance measure). HRSA is also strongly encouraging RGNs to collect a second variable of medically underserved, e.g., race/ethnicity or public/private insurance.

HRSA understands that an IRB may be required to collect zip code data. The NCC and RGNs will work together in this process. NCC is prepared to offer TA.

How will ECHO activities be counted?

ECHO activities can be didactic learning sessions, as well as case consultations. For those sessions that are presented for education/training purposes, they will be counted in measure 1.a. Where cases are presented for diagnosis, treatment and/or care management, these case discussions will be included in measure 4 as teleconsultation.

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1.a: Number of providers, individuals, and families that received education or training on genetics from the RGN program

Goal	Increase the number of providers, individuals, and families using RGN resources	
Definition	Numerator	Number of providers, individuals, and families that received education or training on genetics from the RGN program, cumulative since start of program
	Denominator	—
	Unit Type	Number
	Unit Number	—
Notes	<ul style="list-style-type: none"> • Education and training in telehealth/telemedicine are counted in measure 3. • List of included education and training that “count” for this measure are: <ul style="list-style-type: none"> ○ Active/Registered Participants in the following educational sessions: <ul style="list-style-type: none"> ▪ In-person training sessions ▪ Webinars ▪ On-line courses ▪ ECHO educational sessions (note that these are the didactic learning sessions; case consultations are included in measure 4) • Name and date of the training should be recorded • In terms of counts: <ul style="list-style-type: none"> ○ Collect separately for providers and individuals/families ○ Actual/Precise count from each event ○ Duplicated count of individuals will be allowed for measure (ie if one individual attends two RGN educational events, they can be counted twice.) ○ Annual meeting participants should be recorded once, and not in separate sessions of the annual meeting. ○ Vendors are not considered providers and should not be included in annual meeting counts. ○ High school students should not be included in this performance measure. 	
Data Source	RGN input to NCC REDCap	
Stratifiers for registered participants	<ul style="list-style-type: none"> • Individuals/Families <ul style="list-style-type: none"> • Zip code for individuals/families - rurality, state, region • If zip code cannot be submitted, medically underserved individuals/families zip code checkbox – Yes/No • Genetics/ Non-genetics providers <ul style="list-style-type: none"> • Provider specialty/type <ul style="list-style-type: none"> ▪ Genetic providers: MD/DO, PhD, genetic counselors, other (NPs, PAs, dietitians, and others that work in genetic practices/settings, e.g., MSW) • Non-genetics healthcare providers: 	

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	<ul style="list-style-type: none">▪ Primary care providers: (MD/DO pediatrics, family medicine, internal medicine, general medicine) NPs, PAs, dietitians, and others that work in primary care practices/settings, e.g., MSW)▪ Non-genetics specialty (MD/DO cardiologist, etc.), NPs, PAs, dietitians, and others that work in specialty practices/settings, e.g., MSW)▪ Other settings<ul style="list-style-type: none">• Public health• Other (Community Health Workers, administrative staff)• Zip code for providers should be recorded for PRIMARY practice location site (one zip code) - rurality, state, region.• Zip code for genetic counseling students or other professional students (e.g., public health, medicine, nursing) should be recorded for the school attended.• Provider works in a primary care setting Yes/No• CEUs, CMEs, MOCs awarded
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Measure 1.b: Number of resources on genetics used/accessed from the RGN program

Goal	Increase the number of providers, individuals, and families using RGN resources	
Definition	Numerator	Number of RGN resources used/accessed by providers, individuals, and families, cumulative since start of program
	Denominator	—
	Unit Type	Number
	Unit Number	—
Notes	<ul style="list-style-type: none"> • Education and training in telehealth/telemedicine are counted in measure 3. • List of included resources that “count” for this measure are: <ul style="list-style-type: none"> ○ Website home page visits- Primary required <ul style="list-style-type: none"> ▪ Secondary websites, regardless of when the project was funded, can be counted by the RGN ○ Website unique visits- Primary required <ul style="list-style-type: none"> ▪ Secondary websites, regardless of when the project was funded, can be counted by the RGN ○ National meeting poster and oral presentations (indicate meeting name and sponsorship) ○ Publications (by name) ○ Downloaded resources (count all resources available; regardless of year developed) <ul style="list-style-type: none"> ▪ Apps ▪ PDFs (by name) ○ Recorded webinars/courses accessed (by name) ○ Social media analytics <ul style="list-style-type: none"> ▪ LinkedIn Discussion ▪ Facebook reporting (see separate instruction sheet) <ul style="list-style-type: none"> • Reach • Impressions • Engagement ▪ Twitter followers ▪ You Tube Video Views • Annotate the materials that cover telegenetics <ul style="list-style-type: none"> ○ Meeting presentations ○ New telegenetics resource documents ○ Downloaded resources on telegenetics ○ Recorded telegenetics webinars 	
Data Source	RGN input to NCCREDCap	
Stratifiers	State based on Google Analytics for website activity	

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Measure 2: Number of patients for whom the RGN program facilitated connections to a geneticist or provided initial genetic services

Goal	Increase the number of patients receiving services	
Definition	Numerator	Number of patients for whom the RGN program facilitated connections to a geneticist
	Denominator	—
	Unit Type	Number
	Unit Number	—
Notes	<ul style="list-style-type: none"> • Counts of patients: <ul style="list-style-type: none"> ○ Actual/precise count of NEW genetic patients that are supported by the RGN via <ul style="list-style-type: none"> ▪ RGN salary support ▪ HRSA-originated funding (subcontracts) ▪ RGNs must submit justification to NCC for patient counts that are attributable to infrastructure or technical support. • Facilitated connection defined as: <ul style="list-style-type: none"> ○ Referral ○ Assessing family needs (screener tools/survey) and providing referrals ○ Initiating a conversation and assisting a family in taking to their PCP and possible referral ○ Phonenumber • Genetic services defined as: <ul style="list-style-type: none"> ○ In-person services provided through funded outreach clinic ○ In-person services provided by funded/contracted geneticist <ul style="list-style-type: none"> ▪ Notes for genetic services: <ul style="list-style-type: none"> • Do not include telemedicine services- telemedicine services reported under PM5. • Only count new patients/visits- New patients are those seen for the first time or those for whom a second or third visit would not have been possible with the RGN support (e.g. helping fund a clinic). If a patient already is an established patient with the provider/clinic (ie., has been seen by the provider or clinic), they should not be counted. • Only count new patients seen by RGN-funded geneticists. • By counting new patients every year, enables us to sum the number of new patients served over the grant cycle. • RGNs should estimate/calculate the overlap of people counted in measures 2 and 5 because these numbers are being summed to establish the year 	

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	one- baseline for the family/individuals served and in subsequent years to calculate total numbers of family/individuals served.
Data Source	RGN input to NCC REDCap
Stratifiers	<ul style="list-style-type: none"> • Individuals/Families <ul style="list-style-type: none"> • Zip code for individuals/families - rurality, state, region • If zip code cannot be submitted, medically underserved individuals/families zip code checkbox – Yes/No • Other medically underserved variables: race/ethnicity or public/private insurance

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Measure 3: Number of providers trained in an RGN-supported event that focuses on telehealth modalities for genetics

Goal	Increase the number of providers that are trained to use teleconsultation/telemedicine for genetics services.	
Definition	Numerator	Number of providers trained through an RGN-supported event in either teleconsultation or telemedicine, cumulative since start of program
	Denominator	—
	Unit Type	Number
	Unit Number	—
Notes	<ul style="list-style-type: none"> • “Telehealth modalities” include: <ul style="list-style-type: none"> ○ teleconsultation (provider to provider consultation) ○ telemedicine (telemedicine directly to patients) <p>Three different telegenetics categories should be counted in REDCap:</p> <ul style="list-style-type: none"> • Telehealth training- sessions that are offered or supported by an RGN to train providers in telehealth. <ul style="list-style-type: none"> ○ Actual/precise count of providers trained through: <ul style="list-style-type: none"> ▪ Western States and Heartland training programs should be counted as one training (ie., the modules and in-person meetings cannot be counted separately). ▪ Other RGN training programs with HRSA Telehealth Resource Centers ▪ In-person training at RGN annual meetings ▪ RGN funding for providers to attend Western States and Heartland training programs ▪ RGN funding for providers to attend other RGN-training programs. ▪ RGN funding for providers to attend training programs sponsored by others. ▪ On-line training modules ▪ Other training modalities • Telehealth education- sessions that are offered or supported by an RGN to introduce providers to telehealth, to recruit them for training. • Telehealth technical assistance- consultation that occurs after telehealth training or other assistance that RGN staff render to support providers in getting started or sustaining their telehealth services. <p>If a provider moves to another region, to be counted in the new region the provider must be supported by the new region.</p>	
Data Source	RGN input to NCC REDCap	
Stratifiers	<ul style="list-style-type: none"> • Education, training, or TA event • Genetics/ Non-genetics providers 	

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	<ul style="list-style-type: none">○ Provider specialty/type<ul style="list-style-type: none">▪ Genetic providers: MD/DO, PhD, genetic counselors, other (NPs, PAs, dietitians, and others that work in genetic practices/settings, e.g., MSW)▪ Non-genetics healthcare providers:<ul style="list-style-type: none">• Primary care providers: (MD/DO pediatrics, family medicine, internal medicine, general medicine) NPs, PAs, dietitians, and others that work in primary care practices/settings, e.g., MSW)• Non-genetics specialty (MD/DO cardiologist, etc.), NPs, PAs, dietitians, and others that work in specialty practices/settings, e.g., MSW)• Other settings<ul style="list-style-type: none">○ Public health○ Other (Community Health Workers, administrative staff)○ Zip code for providers should be recorded for PRIMARY practice location site (one zip code) where they conduct telemedicine - rurality, state, region.○ Zip code for genetic counseling students or other professional students (e.g., public health, medicine, nursing) should be recorded for the school attended.• Provider works in a primary care setting Yes/No• CEUs, CMEs, MOCs awarded
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Measure 4: Number of RGN sites that use telehealth modalities

Goal	Increase the number of RGN-supported sites that use telehealth/telemedicine for genetics services.	
Definition	Numerator	Number of RGN sites that used/provided teleconsultation or provided telemedicine for at least one genetics patient in the past year
	Denominator	
	Unit Type	Number
	Unit Number	
Notes	<p>RGN-supported sites may be</p> <ul style="list-style-type: none"> • Contractual • TA to site <ul style="list-style-type: none"> ○ For inter-regional TA (between two or more regions), a duplicate count may occur. • QI to site • \$ • Equipment • Follow-up to training <p>Site Count</p> <ul style="list-style-type: none"> • Telegenetic sites are defined as follows: <ul style="list-style-type: none"> ○ the originating site is where the patient is seen from (home is a possible location); ○ the distant site is where the specialist is based; and ○ patient encounters via telephone should not be considered telegenetic services. • Actual/Precise count of sites • Collect separately for teleconsultation and telemedicine • Baseline <ul style="list-style-type: none"> ○ RGNs should report data from previous grant cycle (when available), or collected in year 1, to provide a universe of telehealth sites in the region, regardless of RGN support • RGN-supported sites (numerator) <ul style="list-style-type: none"> ○ RGNs will report only those sites that they support, and the year-over-year numerator change is what will be reported. <p>Provider Count</p> <ul style="list-style-type: none"> • Actual/Precise count of providers supported by RGN activities • Provider works in a primary care setting Yes/No • If a provider moves to another region and the original site continues to provide telemedicine, the site will continue to be counted. If that provider begins to provide telemedicine services and is supported by the new region, those visits would count in the new region. 	
Data Source	RGN input to NCC REDCap	
Stratifiers	Sites	

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	<ul style="list-style-type: none">• Site Type• Genetics• Primary Care• Other specialties (e.g. cardiology, neurology)• Mixed type (primary and specialty care)• Patient home• Modality<ul style="list-style-type: none">○ Teleconsultation – provider to provider, including ECHO case consultations○ Telegenetics – provider to patient <p>Provider Count</p> <ul style="list-style-type: none">• Specialty Type<ul style="list-style-type: none">○ Genetic providers: MD/DO, PhD, genetic counselors, other (NPs, PAs, dietitians, and others that work in genetic practices/settings, e.g., MSW)○ Non-genetics healthcare providers:<ul style="list-style-type: none">▪ Primary care providers: (MD/DO pediatrics, family medicine, internal medicine, general medicine) NPs, PAs, dietitians, and others that work in primary care practices/settings, e.g., MSW)▪ Non-genetics specialty (MD/DO cardiologist, etc.), NPs, PAs, dietitians, and others that work in specialty practices/settings, e.g., MSW)▪ Other settings<ul style="list-style-type: none">• Public health• Other (Community Health Workers, administrative staff)• Zip code for providers should be recorded for PRIMARY practice location site (one zip code) - rurality, state, region.• Medically underserved zip code checkbox – Yes/No
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Measure 5: Number of patients for whom telehealth modalities for genetics were used

Goal	Increase the number of patients receiving services through telehealth	
Definition	Numerator	Number of patients who were seen by an RGN-supported provider using telemedicine and the number of patients for whom and RGN geneticist provided teleconsultation
	Denominator	—
	Unit Type	Number
	Unit Number	—
Notes	<p>Counts of patients are for RGN-supported projects only.</p> <p>All patients should be counted for RGN-supported:</p> <ul style="list-style-type: none"> • HRSA-originated funding (subcontracts) and RGN salary support. • MOU (agreement for the RGN to provide services to the clinic in exchange the clinic will provide patient data) • Telehealth training—Provider who received RGN-supported telehealth training • Telehealth education sessions (RGN must demonstrate the correlation between the education and the provider who now sees patients via telehealth) • TA (RGN must demonstrate the correlation between the TA and the provider) • RGN-purchased equipment <p>Patient Counts</p> <ul style="list-style-type: none"> • Counts of patients are for RGN-supported projects only. <ul style="list-style-type: none"> ○ Might not be an unduplicated or actual count; More likely to be totals • For teleconsultation – if multiple patients are discussed during consultation, count all patients; • Inter-state/region and national counts are permissible here as long as those served can be tied to a RGN-supported program and should be attributed to/counted by the supporting RGN. • RGNs should estimate/calculate the overlap of people counted in Measures 2 and 5 because these numbers are being summed to establish the baseline for the family/individuals served. 	
Data Source	RGN input to NCC REDCap	
Stratifiers	<ul style="list-style-type: none"> • Individuals/Families <ul style="list-style-type: none"> • Zip code for individuals/families - rurality, state, region • If zip code cannot be submitted, medically underserved individuals/families zip code checkbox – Yes/No • Other medically underserved variables: race/ethnicity or public/private insurance <ul style="list-style-type: none"> ▪ Insurance coverage at time of encounter Yes/No (for telemedicine only) ▪ Public/Private (for telemedicine only) 	

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FOA Reporting Requirements	As Measured By
Increase by 20 percent the number of primary care providers using RGN resources	Measure 1 a in years 2 and 3 of the grant cycle
May 2018, RGNs serving at least 250 individuals/families May 2020, each RGN provides services to at least 1,500 individuals	Measure 1 a, Measure 2, Measure 5
Increase by 20% the number of medically underserved patients served by each RGN	Measure 2, Measure 5 in years 2 and 3 of the grant cycle
Increase by 20% the percentage of clinical sites that use telehealth/telemedicine to provide genetic services	Measure 4 in years 2 and 3 of the grant cycle, numerator only changes will be used to measure the 20% change.
Increase by 20% the number of medically underserved patients receiving genetic services through telemedicine visit	Measure 5 in years 2 and 3 of the grant cycle

HRSA-17-082 page 4. Reporting Requirements	As Measured By HRSA Performance Measure
RGNs will be expected to provide data on how they are achieving the goals of the program, including collecting information on the following:	
1) Number of individuals or families receiving services within each RGN ⁹	Measure 1.a (family education and training) Measure 2 (facilitated connections to geneticists) Measure 5 (telehealth used for genetics)
2) Number of medically underserved patients receiving services within each RGN	Measure 2 (facilitated connections to geneticists) Measure 5 (telehealth used for genetics)
3) Number of primary care, genetic service providers, and public health officials, participating in the regional network infrastructure	Measure 1.a (provider education and training) Should other metrics of participation be collected?
4) Number of technical assistance activities/services provided to genetic service providers	Is this different from 1.a (provider education and training)? Measure 3 (telehealth training) Are there other TA variables to capture?
5) RGN participation in QI activities to connect the medically underserved to genetic services	TBD - counts from NCC-QI project
6) Number of patients/families receiving education and resource materials	Measure 1.a (family education and training)
7) Number of health care providers receiving education or using RGN resources	Measure 1.a (provider education and training)
8) Number of hits on RGN website and social media by stakeholders, providers and consumers	Measure 1.b. (social media analytics)
9) Number of clinical sites that use telehealth/telemedicine to provide genetic services	Measure 4 (clinical sites using telehealth for genetics)
10) Number of medically underserved patients receiving genetic services through telemedicine visits	Measure 5 (patients seen via telehealth)

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