Addressing Gaps in Genetic Services: Regional and National Models in the US

February 2, 2016
1-2 pm ET

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Celia Kaye, MD, PhD, RSSM Workgroup
Overview

1. Background
2. Brief summary of findings
3. Overview of Current RC/NCC Structure
4. Overview of Regional Support Service Model (RSSM) Project
5. Purpose of the WG and project
6. Methodology/process of the WG & AC
7. Priority-setting components
8. Recommendation brief
9. Next Steps- Instructions
Background

National Genetics Education and Consumer Network (NGECN)
• Led by Genetic Alliance
• June 2015- May 2017

National Coordinating Center for the Regional Genetics Services Collaboratives (NCC)
• Led by ACMG

7 Regional Genetics Collaboratives (RCs)
• Housed at University/Public Health Dept.
• June 2012- May 2017

Mission:
1. Strengthen/support the genetics and newborn screening capacity of states
2. Improve availability, accessibility, and quality of genetic services and resources
The State of Services

• Not enough data available
• Not enough genetics providers
  – Increasing demand for services
  – States that don’t have any genetics providers
  – Many are nearing retirement
• Coverage is inconsistent
  – Cost is a significant burden
• Genetic conditions can be complex
Identifying Needs

Community Engagement Process
  – Listening sessions (January-June 2015)
  – Webinar (July 2015)

National Needs Assessments
  – Individual and family needs
  – Provider needs

Objective: Collect actionable data to inform potential functions/services/resources provided of regional centers
  – “Why” and “How” instead of “Yes” or “No”
“Take Aways” from 2013 Survey

• Majority receive care from **multiple providers**
  – Only 1 in 5 people had someone that helped **arrange/coordinate their care**
  – 31.% Very/Dissatisfied w/ **communication among doctors/other providers**

• 42% never or rarely received **social/emotional support** from healthcare provider/support group

• 33% **referred to support** by their healthcare provider

n=1895
Overarching National Needs

• #1 issue experienced around genetic testing = Lack of healthcare providers with knowledge of the genetic condition (33%; n=1231)

• (52.3%; n=1003): VERY HARD to know where to find providers with knowledge about the condition

• BIGGEST BARRIER reported: Lack of providers w/expertise in particular condition (20.3%; n=848)
Sources of Information & Support

• First place looked for information about the condition = **INTERNET SEARCH** (50.3%; n=1129)

• Sources of social/emotional support for condition
  – Support or advocacy organization (29.4%)
  – Fellow parent of individual w/condition (24.0%)
  – Local support group (7.5%)
  – Religious/spiritual figure (7.1%)
  – Counselor (6.0%)
  – Hotline (.1%)

• Did not receive emotional support= 26.1%

n=1213
## Difficulty Finding Information

<table>
<thead>
<tr>
<th>Information</th>
<th>VERY HARD</th>
<th>SOMEWHA'T HARD</th>
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<tbody>
<tr>
<td>Where to find providers with knowledge about the condition</td>
<td>52.3%</td>
<td>25.2%</td>
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<tr>
<td>Information about research/clinical trials</td>
<td>33.3%</td>
<td>30.7%</td>
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<tr>
<td>Information about other types of services/support</td>
<td>33.1%</td>
<td>34.9%</td>
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<tr>
<td>Tests and treatments for your condition</td>
<td>31.6%</td>
<td>29.8%</td>
</tr>
<tr>
<td>What is and what is not covered by your insurance</td>
<td>27.9%</td>
<td>27.8%</td>
</tr>
<tr>
<td>Information about the condition</td>
<td>27.1%</td>
<td>31.5%</td>
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N=1003
Accessing Services and Supplies

Difficulty obtaining services/supplies in the past 12 months?

**VERY HARD** to obtain:

**#1.** Specialist visits (30.3%)  
**#2.** Social/emotional support (support group, family member, etc.) (30.1%)  
**#3.** Therapies (physical, occupational, behavioral, etc.) (25.9%)  

n=848
Patient Navigation

• Services/support that would be most helpful:
  • Help understanding the condition and where to find relevant resources/supports (37.4%)
  • Recommendations for local genetics/medical professionals (14.2%)

• From whom they would be most comfortable receiving information:
  • 1. Fellow parent or individual w/ a condition (36.0%)
  • 2. Care coordinator w/in specialist’s office (29.1%)
Gene specialists have offered telemedicine.

- 91.0% of patients are willing to receive gene services at nearby clinical sites.
- 62.8% of patients are willing to receive services at home.
- 67.6% of patients are willing to receive services at home.

- 4.5% of patients prefer telemedicine.
- 4.6% of patients prefer on-site services.
- 91.0% of patients prefer telemedicine.

- 14.7% of patients prefer on-site services.
- 17.7% of patients prefer telemedicine.

n=920
Adult Care

Biggest issues reported accessing adult care:

1. Finding providers w/ expertise/knowledge of condition (34.6%)
2. Social and emotional health/wellness (21.2%)
3. Costs of care/insurance coverage for needed services (18.2%)

• 36.9% of individuals who needed help identifying adult specialists did not receive that help from their primary care provider

N=856
Current Efforts

• Patient navigation landscape analysis
• Refresh and build out of DiseaseInfoSearch.org
• Study on impact of referral to support
• Accessible genetics education
• Capacity building on public health genomics
June 1 2015, NCC and its partner, the National Genetics Education and Consumer Network (NGECN, housed at Genetic Alliance) began to consider what models for future regional genetic service centers might look like.

Task, by March 2016, to provide a recommendations brief of models for future genetic service centers.

Convened a Regional Support Service Model Workgroup (RSSM WG) and Advisory Committee (AC), led by Dr. Celia Kaye
The NCC Regional Support Service Model Workgroup (RSSM WG) will review existing models of regional care (public health and direct service-based) with the goal of identifying populations served, organizational structure, services provided, center budget, communication model, and evaluation and outcome metrics. Based on this review, the RSSM WG will develop a recommendation for a model or models for regional centers that will enhance access to genetics care, particularly for populations that have limited access to genetic services due to geographic, economic, cultural or other barriers. This recommendation or set of recommendations will reflect the needs of diverse regions and stakeholders.
Purpose of the Workgroup

The purpose of the NCC RSSM Workgroup is to bring together a broad range of genetics stakeholders to consider and develop recommendations for a framework of regional genetic services that reach underserved populations.
Process: RSSM WG and AC

• Consider recommended regional models
  – Derived from listening sessions held by NCC and NGECN January through July 2015 with more than 250 participants representing consumers, healthcare professionals (genetic and non-genetic), and public health. NCC subject matter workgroups also contributed suggestions.

• Review national needs assessments to understand identified gaps
  – National needs assessments conducted by NCC and NGECN Fall 2015.

• Develop recommendations for components of models to ensure access to genetic services for underserved populations.
  – February 2016: Recommendation brief available for comment
  – March 2016: Final Brief provided to HRSA
NCC Recommendation Brief

• Identification of needs and priorities
  – Priorities identified through the national provider and consumer needs assessments
  – Priorities refined through iterative rating process (RC PD/PMs, RSSM workgroup, RSSM AC, GC students)
  – Priorities:
    • Formal Relationships
    • Education and Training
    • Promoting Family Engagement
    • Practice Support
    • Efficient Practice
    • Data Collection
NCC Recommendation Brief (2)

- Relationship of Priorities to MCH Pyramid

![MCH Pyramid Diagram]

Legend: Priority Addresses:  | Priority Does NOT Address:  
--- | ---
Recommended Models

– Regional Genetic Service Resource Network (regional infrastructure with a central coordinating body)
– Regional Clinical Support Centers (efficient practice)
– Regional Genetics Education and Technical Assistance Centers (education focus, similar to ECHO)
– Regional Patient Engagement Centers (Consumer-focused)
– Public Health Model (address public health concerns, state public health partnership focus)
– Quality Improvement Model (e.g. Pathways, PCORI-related)
– Regional Clinical Support Network (e.g. hemophilia networks)
– Genetic Service Data Centers (data, find out where patients are and when they get services, carefully selected information)
## Model 1: Regional Genetic Service Resource Network

<table>
<thead>
<tr>
<th>Description</th>
<th>Pros</th>
<th>Cons</th>
<th>Priorities Addressed</th>
<th>Timeline/Time Requirements</th>
<th>Time to Implementation (Access Projects)/Initial Data Collection</th>
<th>Outcomes</th>
<th>Promotion of Efficient use of Resources</th>
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<tbody>
<tr>
<td>Central coordinating body and regional centers.</td>
<td>Team approach</td>
<td>Current RCs still not widely known; use of this structure would require aggressive promotion of the system in order to improve access</td>
<td>Priority 1</td>
<td>1 yr to develop infrastructure if current infrastructure not used</td>
<td>Up to 1 year: infrastructure</td>
<td>Highly variable; dependent upon what activities/priorities are pursued (see sub-categories below)</td>
<td>May take advantage of existing infrastructure</td>
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<tr>
<td>Regions work with states, providers and consumers to develop a team composed of a wide array of stakeholders</td>
<td>Familiar structure for current HRSA regional collaboratives and other centers; would permit HRSA to build on what has been learned, using existing or similar infrastructure</td>
<td>May address Priorities 2, 3, 4, and/or 5, depending on HRSA goals and regional needs</td>
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<td>1-4 years—dependent upon whether a regional system focuses on data collection; care delivery; patient engagement</td>
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<td></td>
<td>Looks at a wide range of issues/priorities</td>
<td>Identifying common elements to measure outcomes could be difficult. Some consistency with other HRSA programs also desirable.</td>
<td>Priority 6</td>
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<td>Region could focus on what is lacking most for the region within the context of the goals of HRSA</td>
<td>Lack of consistency in outcomes could affect funding in the long run</td>
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<td>Training could be administered readily; fellowships could be supported as well; genetic counselor training could also be supported</td>
<td>Demonstrating national impact difficult if regional activities highly variable</td>
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<td></td>
<td>Center could be used to facilitate relationships between states, genetics providers, non-genetics providers, consumers, other existing programs</td>
<td>Work needs to be done within the healthcare delivery system to impact access</td>
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<td>Demonstrating national impact is achievable if common goals/objectives</td>
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Model 2: Regional Clinical Support Centers

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<tbody>
<tr>
<td>Central coordinating body and regional centers. Focus is on clinical providers, public health genetics or both. Activities limited to administration, technical assistance, clinical support, care coordination, evaluation, and workforce capacity.</td>
<td>May address workforce capacity</td>
<td>May not be needed in all regions</td>
<td>Priorities 1, 3, 4, 5, and 6</td>
<td>1 year for infrastructure development, assuming current regional structure and coordinating center not involved</td>
<td>2-3 years</td>
<td>Improved workforce efficiency</td>
<td>Takes advantage of existing clinical centers, supports their need for more efficient practice</td>
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<tr>
<td>• May address workforce capacity</td>
<td>• Limits services provided to other specialists and primary care providers</td>
<td>• Education component for non-geneticists is not covered</td>
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<tr>
<td>• Promote efficiency</td>
<td>• For some payers, a national system may be ok</td>
<td>• Patient engagement component is left out</td>
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<td>• Most ability to get data for individual sites- clinical site data</td>
<td>• Plans vary so may not be able to provide national data on some access issues</td>
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<td>• Other product development possible</td>
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# Model 3: Regional Genetics Education and Technical Assistance Centers

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</table>
| Central coordinating body and regional centers. Serves both clinical providers and public health entities. Activities limited to administration, education, technical assistance, evaluation. Focus is education-development of materials, ECHO, just-in-time services, public education at right place right time. | • Easier to do than some other suggested models  
• Much of work could be done using on-line methodology  
• Would maximize impact of limited dollars  
• Potential for broad reach  
• Broad expertise exists in the field  
• Simpler system: billing/reimbursement is difficult but straight education is easier  
• Providers need just-in-time materials; webinars could be used | • Focusing on providers and public education means we could miss consumers; need to include consumers in education  
• Difficult to measure behavior change following an educational program; difficult to show clinical impact (improved access)  
• Disease-specific educational materials are more beneficial but can be difficult to develop  
• Need capacity to develop and distribute just-in-time materials at sites where needed  
• Would have to be driven by other national organizations (AAP) to get into training programs | Priorities 1, 2, 5, and 6 | 1 year for infrastructure development, assuming current regional structure and coordinating center not involved  
1 year – identification of key activities/priorities  
1 year-action plan and evaluation developed | 2-3 years | Broad reach to providers and public health  
Improved genetic literacy and knowledge as demonstrated by pre and post testing and surveys | Maximizes impact of limited dollars  
Potential for broad reach |
## Model 4: Regional Patient Engagement Centers

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<th>Description</th>
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<tr>
<td>Central coordinating body with regional centers. Primary partners may be Genetic Alliance, public health departments or both. Activities limited to administration, patient engagement including care coordination, education with focus on consumer issues, evaluation. Focus on the consumer</td>
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<table>
<thead>
<tr>
<th>Pros</th>
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<tr>
<td>Addresses some high need areas based on feedback from the survey; people aren’t getting information they want/need (low literacy, other languages)</td>
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<table>
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<tr>
<th>Cons</th>
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<tbody>
<tr>
<td>Difficult to address in stand-alone centers</td>
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<tr>
<td>Outcome measures may be difficult</td>
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<tr>
<td>Information-seeking individuals will be helped but may not reach entire population</td>
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<tr>
<td>If workforce capacity issue isn’t addressed, an influx of people could be entered into the system without appropriate workforce</td>
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<td>Not addressing clinical/delivery systems; therefore doesn’t address underlying issues</td>
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<th>Priorities Addressed</th>
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<tbody>
<tr>
<td>May address Priorities 1, 2, 3, and 6</td>
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<thead>
<tr>
<th>Timeline/Time Requirements</th>
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<tbody>
<tr>
<td>1 year for infrastructure development, assuming current regional structure and coordinating center not involved</td>
</tr>
<tr>
<td>1-2 years – identification of key activities/priorities</td>
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<tr>
<td>1-2 years-action plan and evaluation developed</td>
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<table>
<thead>
<tr>
<th>Time to Implementation (Access Projects)/Initial Data collection</th>
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<tr>
<td>2-3 years</td>
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<thead>
<tr>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Addresses some high need areas based on feedback from the survey: people aren’t getting information they want/need (low literacy, other languages)</td>
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<thead>
<tr>
<th>Promotion of Efficient use of Resources</th>
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<tbody>
<tr>
<td>Activities may overlap with Genetic Alliance, NEGCN, other national and state projects</td>
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<tr>
<td>Potential outcome measures include access to services</td>
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## Model 5: Public Health Model

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<th>Pros</th>
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<tbody>
<tr>
<td>Could be only a central coordinating body, only regional centers, or both. Primary partners are state health departments. Funding supports a state genetics coordinator in each state.</td>
<td>Enhanced data collection by state genetics coordinators. Increased access to individuals not getting services through coordination with Title V, Medicaid, and chronic disease programs. Many issues preventing access are at the state level. In a mixed model, some regions could support programs to provide information to state public health as needed by individual states. Easy access to other large public health programs (Medicaid, Title V). Helps build relationships within state health departments and may provide access to other state budgets for specific programs (if genetics program budget isn't available); once matured it is a return on investment. Regional centers would have no control over states but NCC/RC system has built state NBS capacity, suggesting this is a feasible model. Structure within states can be a sustainable model.</td>
<td>Some states may be unwilling or unable to accept small amounts of money available through these grants. Some states may not wish to accommodate this position within their state structures. There needs to be a state champion for genetics beyond the coordinator. Success is dependent on genetics coordinator being high enough in the state structure to be effective. May have an issue filling 50 slots for coordinator with a trained genetic counselor (workforce issue). Salary may not be as competitive as industry. May need to recruit professionals with other backgrounds. Coordinator requires time to develop relationships, work with other units in the department to create/fund programs to address clinical, educational needs</td>
<td>Priorities 1 and 6. May address Priority 2 and other priorities depending on priorities of state health departments, needs identified, HRSA priorities</td>
<td>2 years to establish an infrastructure and build partnerships/relationships to put a genetics coordinator in a state public health office. 2+ years—embed state genetics coordinator in state public health and develop activities/priorities for that work.</td>
<td>Initial data collection: 2+ years. Implementation of access projects: 3-4 years.</td>
<td>Enhanced data collection by state genetics coordinators funded by these grants. Enhanced coordination with Title V, Medicaid, chronic disease programs, where some access problems exist.</td>
<td>Would take advantage of state resources in those states receptive to this model. States vary greatly in current commitment to genetic services; this would need to be taken into account when funding decisions made.</td>
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<tr>
<td>Description</td>
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| Central coordinating body and regional centers. Data collection and grant activities focused on plan to develop, implement and evaluate formal quality improvement processes to improve access. | - Validated method, evaluation built in, outcomes reportable.  
- Could put almost any activity around access into a pdca. (pre-data collection, QI effort would address a specific problem, as opposed to all problems.)  
- Development of metrics in genetics would be useful.  
- Single national unified project would permit national data collection and outcomes assessment  
- Could permit coordination with MOC activities for providers  
- Many access problems could be addressed using QI methodology | - Higher cost  
- Would require a planning phase, lag likely in getting to data collection (identify methodology first, then start data collection)  
- Genetics professionals unfamiliar with QI and Implementation science would require additional education.  
- Measurable outcomes from QI project might not immediately promote access.  
- A single national QI focus may not be applicable to all regions. However, selection of regional QI projects would limit national data collection and outcomes assessment  
- Systemic issues related to genetic access seem too big for some QI approaches  
- Could end up with a number of pilot projects that might differ. Local data easy to get, but national data difficult to collect. | Priorities 1 and 6  
Priorities would depend on what the QI program would address. | 1 year for infrastructure development, assuming current regional structure and coordinating center not involved.  
1 year—planning  
1-2 years—recruitment and intervention  
1 year—evaluation | 4 years (per PDSA cycle)*  
*Because standard quality measures do not exist for many quality improvement goals, additional time would be required in the first cycle to establish these goals and identify methodology. | Demonstration of effectiveness of specific QI initiatives related to access, assuming clinical genetic centers willing to participate.  
May exacerbate workforce problem | Would require development and implementation of QI methodology related to genetic access, implementation nationally |
# Model 7: Regional Clinical Support Network

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<tbody>
<tr>
<td>• Focused on clinical service; local/state clinics apply for funds from regional centers to meet their specific and unique needs</td>
<td>• Trackable outcomes as long as effectively communicated between center and clinics</td>
<td>• Regional centers focus on contracting and evaluating (less than 12 months to contract, complete the work, evaluate)</td>
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<td>1 yr, development of infrastructure if current infrastructure not used</td>
<td>2 years</td>
<td>Trackable outcomes as long as effectively communicated between center and clinics</td>
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<tr>
<td>• Regions coordinated by a central coordinating body</td>
<td>• Could enhance funding already in place if state does have contract funding</td>
<td>• A lot of contracts with very little money depending on the state; could enhance the maldistribution of dollars</td>
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<td>1-2 years—clinical center identification, recruitment, contracting</td>
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<td>• HRSA could define specific goals for system</td>
<td>• States could coordinate their support of genetic services with resource centers, so that funds could be equitably distributed</td>
<td>• Because clinical centers must apply for funds to meet their specific needs, funds may not be distributed to the communities efficiently or equitably</td>
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<td>• Takes advantage of mechanisms already in place in some states to contract out services</td>
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# Model 8: Genetic Service Data Centers

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| Central coordinating body and regions. Central body works with HRSA to determine data of interest, who has national data sources. Regional centers work with clinical entities, consumers, states to collect data. Goal is to collect data related to access to genetic services. Different data from NBSRN and CDC surveillance, to include finding out where patients are, their demographic and clinical characteristic, and when they get service i.e., Regions 4 and 6 mapping projects, Carefully selected information could have one central data center to which all regional centers report data. | - Gets national, uniform baseline data  
- Allows measurement of impact of future programs  
- Data for policy development  
- National data set would be useful in informing the greater medical community  
- Could address health equity issues - drill down to different conditions, populations to identify regional and local needs  
- Reinforce formal relationships with state programs, can create data together so may not need to give money to state  
- Works well with meaningful use standards  
- Delays action steps until baseline data collected | - Does not improve access initially - no "action" steps until data are collected and analyzed to identify needed actions  
- Long-term results will be years from initiation of grant cycle; therefore more difficult to get buy-in from partners who would need to provide data  
- Would need to build in time to choose core data set (what to collect and from whom). Also need time to define and create formal relationships with clinical programs and states.  
- Would have to pay for data entry into a regional/national repository  
- This would be an all-consuming endeavor, and would obviate all other activities.  
- States often don't have data on non-nbs conditions; would require data from clinical sites and other sources | Priorities 1 and 6 | 1-3 years for infrastructure/database development  
1 year-recruitment | 1-3 years for infrastructure development, depending on database structure selected  
Data collection could begin in years 2-3  
Multiple years of data collection and analysis required (5+ years for full project) | Gets national, uniform baseline data  
Allows measurement of impact of future programs  
Data for policy development  
National data set would be useful in informing the greater medical community | There may be other funding mechanisms within HRSA or CDC better suited to this activity. |
Recommendation 1:
• The workgroup recommends the adoption of a hybrid of models 1, 2, and 3 with a primary focus on: promotion of efficient practice within genetic centers (TA for telegenetics, TA for authorization of genetic testing and other genetic services, TA for genetic counselor licensure and billing; and other as ID’d through interaction with genetics providers); and aggressive and targeted support of non-genetics providers through promotion of their relationships with genetic centers, provision of point-of-care decision support, and development of other tools to enhance the level of care than can be delivered in conjunction with, but outside of the genetics center itself.

Recommendation 2:
• Regionalized structure for future programs.

Recommendation 3:
• Central Coordination provides a key function.
Recommendation 4:
• Function of genetic services support centers within the healthcare delivery system and the role of public health.

Recommendation 5:
• Provision of non-genetics provider education.

Recommendation 6:
• Data collection

Recommendation 7:
• Support for increasing the number of physician geneticists, genetic counselors, and other highly-specialized providers for treatment of genetic disorders.
Let Your Voice be Heard and Share your Opinion

- Draft Recommendations Brief is now available on the NCC website: www.nccrcg.org
- Read the brief; and,
- Provide your comments, thoughts, ideas, suggestions no matter how brief or extensive from February 1-26, 2016.
- Submit your comments to: ncc@nccrcg.org
Final Deliverable

• March 2016—deliver to HRSA a recommendations brief that discusses potential regional support service models sharing pros/cons and costs (where possible)
Questions/Discussion
Thank you

We aim to reflect the needs and priorities of the stakeholders within the genetics community. Please provide your comments on the brief to:

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