

**Strategic Planning Recommendations from  
HRSA's Regional Genetics and Newborn Screening Service Collaboratives  
and their National Coordinating Center**

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## Contents

Executive Summary.....	1
Background .....	2
Summary of NCC/RC Past Accomplishments and Challenges.....	3
Successes .....	3
Challenges .....	4
NCC and RC Suggested Areas of Focus .....	5
Addressing HRSA's Priority Areas: .....	5
Additional Areas of Focus .....	8
Changing Models of Delivery of Genetic Services.....	9
Improving the Delivery of Genetic Services:.....	11
NCC and RC Suggestions for Improving Collaboration.....	12
Guiding Recommendations for the Future.....	13

Appendix A: NCC / RC Survey Tool

Appendix B: NCC / RC Survey Results

## Executive Summary

This document provides a summary of recommendations offered by staff and leadership of the Regional Genetics and Newborn Screening Service Collaboratives (RCs) and their National Coordinating Center (NCC) for the purpose of assisting HRSA in its long range strategic planning efforts. The material draws from two major sources of information: 1) a survey of the NCC and the seven RCs administered in November 2010; and 2) a national NCC/RC Project Director/Project Manager meeting held on November 18th, 2010. Data collection efforts and analysis was led by Peter Antal, Ph.D., of the Institute on Disability at the University of New Hampshire, with support from Alisha Keehn and Gloria Weissman from the NCC, housed at the American College of Medical Genetics. Additional support was provided by a planning committee comprised of RC and HRSA leadership. This report covers the following areas and expands on the suggestions and recommendations from each area highlighted below:

- **Major Success and Challenges of the NCC/RCs:** This section provides background information on the broad range of activities undertaken across the U.S. over the history of the initiative, as well as some of the challenges encountered by staff of the NCC and RCs.
- **Suggested Areas of Focus:** Material in this section provides: staff feedback on supporting HRSA's four priority areas; additional areas of support needed to improve genetic services; and group feedback around the need to establish innovative models of care. Key themes from this section include:
  - clarifying the needs that will be addressed, reducing duplicative work, prioritizing resources, clearly defining life course issues, and framing the link between genetics education and health outcomes;
  - considering how current NCC/RC projects should or should not fit into the next phase of activities;
  - empowering state public health professionals in the NBS system (including long-term follow-up) through focused training, forums for collaboration, and increasing the workforce pipeline using innovative approaches;
  - providing clear direction on the roles of the NCC and the RCs.
- **Recommended Domains and Theme Areas:** Based on a review of the available data, seven major domains were identified as focus areas for future change efforts. These domains include:
  - providing services over the life course;
  - targeting specific areas of change (such as health care reform or workforce improvement);
  - enhancing the infrastructure of participating organizations;
  - improving the quality of care;
  - improving access to care;
  - collaborating with a range of partners; and
  - educating multiple audiences in society—including consumers and professionals— about genetics and genomics.
- **NCC and RC Recommendations for Improved Collaboration:** Based on their experiences to date, staff from the NCC and the RCs offered their thoughts on how to improve communication, integration, and funding disbursement across the organizations involved in this effort.
- **Guiding Recommendations for the Future:** Provides several discussion questions for HRSA staff to consider. These include a look at:
  - the importance of HRSA determining national priorities for the RCs and the NCC; and
  - how prescriptive HRSA should be to ensure that all organizations are working towards the same end, while still recognizing the need for, and benefits of, flexibility and innovation at the regional level.

## Background

The seven RCs and the NCC were initially funded in 2004. The main goal of this initiative was to improve access to newborn screening and genetic services, especially for medically underserved populations. Each RC was expected to: (1) enhance newborn and child screening and related follow-up services for heritable disorders, including an expansion of long-term follow-up activities; (2) augment workforce capacity through such activities as training and education; (3) enhance subspecialty access by strengthening linkages between medical homes and tertiary care centers; (4) enhance genetic counseling services; and (5) strengthen state programs' communication and education to families and health practitioners. Each RC was also to be responsible for providing the states in its region with access to genetic medicine expertise for subspecialty care and for the ongoing treatment and management of children identified with genetic disorders through newborn and other screening programs (Puryear, Weissman, et al, 2006). Finally, the RCs were to be responsive to the legislative authority that defined the Heritable Disorders Program under the Children's Health Act of 2000. The RCs and the NCC were funded for a period of three (3) years.

The second stage of HRSA's Regional Genetics and Newborn Screening Services initiative began in 2007. Once again, seven collaboratives, now known as the Regional Genetic and Newborn Screening Service Collaboratives (RCs) and a National Coordinating Center (NCC) were funded, this time for a period of five (5) years. The RCs are still expected to be responsive to the priorities of the Heritable Disorders Program and to enhance and support the genetics and newborn screening service capacity of States across the nation. A major goal of the seven RCs is to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home. In order to accomplish this goal, the Genetic Services Branch (GSB) requires that the RCs: (1) strengthen communication and collaboration among public health, individuals with genetic disorders, families, primary care providers, and genetic medicine and other subspecialty providers; and (2) quantitatively and qualitatively evaluate outcomes of projects undertaken to accomplish their goals.

In considering next steps for this effort, HRSA has been leading a strategic planning process to determine how best to structure its future efforts and to identify which areas are most in need of support. As a part of this process, a range of perspectives have been sought from the RCs and the NCC on how to use HRSA's resources to improve access and utilization of high quality genetic services. The RCs and the NCC provided feedback both through a national survey and a collaborative discussion held November 18, 2010, as part of the annual NCC/RC Project Director/Project Manager meeting.

The survey was administered in November 2010 to all the RCs and the NCC. Respondents were asked to include a range of perspectives from their region when responding (a copy of the survey as well as a brief summary of results are included in the Appendix). Reflecting the unique orientation of each RC, some RCs aggregated responses from their staff only, others asked their advisory groups/committees to respond, and others were a mix. The chart below reflects the variation in respondent types<sup>1</sup>:

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<sup>1</sup> The response time for the survey was less than one week, this impacted the ability of some RCs to secure broad stakeholder review and input.

Type of Respondents	# of RCs and NCC
Aggregate (RC Staff submitted one survey)	2
Aggregate (including RC stakeholders and partners in addition to staff—family advocates, health care professionals, and state public health programs)	1
Aggregate and individual responses	4
RC Advisory Committee	1

Results of the survey were used by the Planning Team (made up of representatives from the RCs, the NCC, and HRSA) to guide a November 18th discussion of the NCC and RCs. Of note, this document is meant to reflect the perspectives of HRSA's seven Regional Genetics Collaboratives and their National Coordinating Center. The perspectives of a broad group of grantees supported by MCHB's Genetic Services Branch, as well as those of other stakeholders, were collected at earlier meetings. Information gathered from all of these efforts will be combined by the Genetic Services Branch to inform their long-term strategic plan.

## Summary of NCC/RC Past Accomplishments and Challenges

### Successes

In carrying out their work to-date, the RCs and the NCC have been successful in implementing a range of important activities. RCs have made positive change in the areas of:

- (1) building critical networks and collaborations;
- (2) identifying, supporting, and even creating new resources for delivering care for individuals with genetic conditions;
- (3) producing approximately 180 publications and presentations documenting improvements in the body of knowledge on genetic services;
- (4) consumer and provider training;
- (5) emergency preparedness;
- (6) improving long-term follow-up systems;
- (7) supporting innovative projects;
- (8) improving screening, diagnosis, and clinical care; and
- (9) data gathering.

The NCC has assisted the RCs by:

- (1) building an infrastructure for collaborative partnerships between the regions and HRSA;
- (2) creating multiple venues for cross-RC work;
- (3) conducting an overall evaluation of the initiative; and
- (4) pursuing discrete projects (ACT sheets, GIM supplements).

There have also been significant regional efforts to achieve sustainability of key program components. The RCs have sought to ensure the sustainability of their efforts by: strengthening how they do their work

### RC Tools of Change

*In carrying out their work during the first two rounds of funding, RCs pursued a number of different avenues to bring about individual and systems change, including:*

- Delivering Services
- Training
- Education
- Research to Practice
- Piloting Models
- Using Technology
- Direct Funding
- Legislation
- Collaboration Building
- Advocacy
- Sustainability
- Family Involvement
- Supporting State Efforts
- Presentations and Publications
- Using Content Experts

(through use of experts, strategic planning, collaboration, and documentation); adopting a range of dissemination efforts (publications, web postings, trainings, national workgroup participation); providing support to partners (funding for others to learn about their work, providing technical assistance, and keeping products current); and integrating the promising practices developed and lessons learned into other regional or national initiatives.

## Challenges

While the RCs and the NCC have been successful in a range of areas, they have also encountered some substantive challenges at the individual, state, regional, and national levels. RC leadership have struggled with determining how best to engage and involve consumers and families, how to effectively manage the time of RC participants, and how to maintain engaged volunteer leadership. At the state level, the RCs have found it difficult to affect change in those areas:

- (1) over which they do not have direct control (e.g., developing state genetic plans, working with state agencies that are unable to actively coordinate their work with that of the RCs, dealing with state budgets that limit the ability of state partners to travel);
- (2) where the funding structure does not enable them to be responsive to state public health needs; and
- (3) where a state is focused on initiating new programs rather than improving existing systems.

Regional challenges that have arisen include:

- (1) ensuring appropriate representation over time by all states and relevant partners;
- (2) coordinating multiple and diverse projects across the region (particularly in light of priority funding arrangements);
- (3) ensuring fiscal sustainability of successful projects;
- (4) appropriately balancing resources directed towards academic products vs. applied tools;
- (5) needing more technical assistance (especially in the areas of communication, dissemination of products); and
- (6) moving successful regional projects to a national level.

At the national level, critical challenges have existed in terms of communication and coordination among the RCs, NCC, and HRSA (as well as with other organizations); constraints posed by an inadequately funded health care system (e.g., lack of single payer universal health care, lack of financial support for clinic or data entry); and insufficient resources to both sustain important initiatives that have a national impact and to support promising new projects.

The NCC also cited challenges that it encountered during the course of its work with the RCs and HRSA. These included:

- (1) a lack of clarity about the role of the NCC (e.g., its mission beyond working with the RCs);
- (2) limited understanding of the education and policy needs of the RCs;
- (3) communication challenges (related to geographic distance, website limitations, cross-group collaboration);
- (4) a lack of consistent protocols for “nationalization” of successful regional projects; and
- (5) a limited sense of collaboration between some RCs and the NCC (sometimes due to funding scenarios that created conflict).

## NCC and RC Suggested Areas of Focus

### Addressing HRSA's Priority Areas

The survey administered to NCC and RC staff asked for feedback on potential roles that they could take relative to HRSA's four priority areas. The four priority areas include:

- *Improve Genetic Literacy of the Public* so they can make informed, quality decisions about genetic testing and services.
- *Advance the Genetic Literacy of Providers* (clinical and public health providers) so they may effectively use genetic information and technology to improve the health of patients and the public.
- *Meet State Public Health Needs* by assisting states in the delivery of genetic services to the whole population and work to improve outreach and follow-up for those identified with inherited conditions.
- *Adopting a Life Course Approach* by enhancing the integration of genetic information and genetic services into health care and public health services provided to individuals throughout the life course.

- From *Creating a Strategic Plan for the Genetic Services Branch*, conference planning document (10/21/10)

The RCs saw a range of potential roles for their collaboratives in these areas, as well as a number of activities already underway relative to the strategic goals. To best set the stage for future successes, the RCs recommended:

- (1) clarifying the needs that will be addressed;
- (2) reducing duplicative work;
- (3) prioritizing resources;
- (4) clearly defining lifespan issues; and
- (5) framing the link between genetics education and health outcomes.

The regions also highlighted the need for:

- (1) enhanced coordination and facilitation by the NCC;
- (2) expanded exploration of public/private partnerships;
- (3) substantive improvements in information systems; and
- (4) improved collaborations with similarly-aligned organizations like the Genetic Alliance and the National Coalition for Health Professional Education in Genetics (NCHPEG).

Of note, several RCs wondered what impact a focus on new initiatives might have on the current work of the RCs and their ability to sustain successful efforts already underway to achieve regional and national goals.

### Improving Genetic Literacy of the Public

In discussing future activities around this first goal of the Genetic Services Branch, survey respondents shared their insights on how to structure these efforts, as well as providing recommendations on some of the critical methods to adopt.

Respondents emphasized the need to adopt a strong collaborative approach among the RCs and national groups such as the Genetic Alliance Newborn Screening Clearinghouse and the National Newborn Screening and Genetics

Resource Center (NNSGRC) to develop and disseminate materials. One of the first steps recommended was to identify existing educational materials at all appropriate literacy and cultural levels for consumers. Once this initial set of materials has been identified, respondents suggested that entry points might include a national public service announcement campaign and delivery through NBS programs. One respondent suggested that efforts should be made to collaborate with curricula developers to integrate genetic information into the public school curriculum. In thinking about "how" to educate the broader public, respondents focused on the importance of collaborating with local educational efforts. Materials must be developed at the appropriate literacy and cultural level for the specific groups of consumers targeted, and consumers should be an integral part of the messaging process in order to help make genetics relevant for the population.

### **Advancing the Genetic Literacy of Providers**

The second strategic goal of the Genetic Services Branch is to educate clinical and public health providers to use genetic information and technology to improve the health of their patients and the broader public. This goal is particularly important in light of rapidly changing knowledge in the field of genetics and potential changes in care delivery models as health care reforms take effect.

Respondents noted that genetic information needs to be integrated into all levels of the medical school and other professional training curricula. Trainings should be targeted to practicing health professionals as well as to trainees, and curricula should include consumer stories. In order to provide and enhance training opportunities for health professionals, a respondent suggested making sure that recertification requirements for health professionals and mid-level trainees include modules on genetic diseases.

One respondent suggested that there is a potential role for genetics membership organizations (e.g., the American College of Medical Genetics) to help disseminate the work and educational resources of the NCC/RCs to providers in the field.

### **Meeting State Public Health Needs**

Expanding and improving the delivery of genetic services will require enhanced collaboration between genetics professionals and state public health agencies. Respondents to the survey discussed what would need to be done in order to improve outreach and follow-up for those identified with inherited conditions. It will be critically important to clarify the respective roles of the RCs, clinical genetic and general practice medicine, and public health (including state newborn screening and genetic programs) in implementing the new paradigms for providing genetic services throughout the life course. In addition, respondents identified some specific areas on which the RCs and state public health departments could work together, including:

- (1) training of state public health professionals in NBS and genetics;
- (2) providing a forum for genetic service providers to meet and collaborate among themselves and with public health professionals;
- (3) campaigning to encourage the interest of young adults in NBS and genetics;
- (4) increasing the public health genetic workforce; and
- (5) expanding the capacity for health information exchange.

## **Delivering Services Via a Life Course Framework**

Moving towards a life course approach to the delivery of genetic services and information will require that HRSA support the NCC and RCs to develop methods for engaging a much broader group of potential consumers of genetic services (and their family members), as well as providers (including federally-qualified health centers and other safety-net providers), private philanthropy, a range of state and local programs, and decision-makers at all levels. Based on feedback gathered from the survey as well as group discussion on November 18th, suggested areas of improvement include:

- (1) an overall focus on decreased morbidity and mortality;
- (2) recognition and adequate funding of genetic programs beyond NBS by public health;
- (3) public service announcements and presentations in schools about genetics and health - one of the potential focus areas would be helping individuals and families to know when they need genetic services;
- (4) ensuring availability of genetic services across the life course (including appropriate and timely screening);
- (5) ensuring a body of providers who are trained in the life course framework, potentially utilizing the NCC to develop registries and to provide CME and maintenance of certification assistance;
- (6) a continued focus on quality improvement, particularly on adult services, to ensure that they are of the same quality and availability as pediatric services;
- (7) improving financing and reimbursement for genetic services by helping insurers understand that appropriately covering necessary services across the life course will benefit their bottom lines; and
- (8) ensuring that people know how to access genetic services.

Additional discussion during the November meeting focused on some of the potential activities to achieve outcomes relative to public health involvement, consistency of services across the lifespan, and delivery of high quality services.

Participants recommended seven actions to support a public health focus on genetic programs beyond newborn screening:

- (1) educate and provide incentives to public health programs to include genetic services;
- (2) add a dedicated genetic service component to Title V and other programs within state public health departments;
- (3) educate geneticists about public health;
- (4) bring public health and geneticists together;
- (5) assess the current state of public health genetics in terms of what does and does not work;
- (6) reach out to epidemiologists in public health agencies and through partnership with local public health schools; and
- (7) extend pediatric databases across the lifespan.

In order to ensure services are available across the lifespan, participants recommended that RCs play a role in documenting the need for adult genetic services, creating well-vetted service directories, and contributing towards the development of an adequate workforce.

When discussing how to ensure that adult services are of similar quality to pediatric services, it was suggested that RCs focus on documenting the quality and availability of pediatric services, defining and making recommendations on what services should be available across the lifespan, and identifying gaps in existing services.

### **Role of the NCC Across the Priority Areas**

NCC staff who responded to the survey felt that the primary role of the NCC should be to support communication and collaboration among the seven RCs and among the RCs and other national organizations. The NCC should track the activities of the RCs and other national organizations and make this information accessible to all the RCs, improving the ability of the RCs to identify common efforts and potential partnerships. Finally, the NCC should facilitate expansion of RC activities by: helping with dissemination of products and information; piloting activities; and identifying appropriate sources of additional funding.

### **Additional Areas of Focus**

In addition to providing recommendations around HRSA's four priority areas, survey responses and group discussion also highlighted the need to work on a number of areas--both broad and targeted-- including moving research to practice; developing regional approaches to the delivery of care; and shaping the infrastructure of health care.

### **Broad Areas to Pursue**

#### Moving Research to Practice

In terms of moving research to practice, respondents emphasized the need to continue: generating new knowledge for the field; collecting and analyzing data on different treatment strategies and their impact on specific diseases/conditions; and developing improved processes for integrating best practice activities into health care systems.

#### Systems of Care

On the topic of systems of care, survey respondents identified the need for:

- (1) education at all levels;
- (2) enhancing communication among providers;
- (3) improving access to care;
- (4) addressing emergency preparedness needs;
- (5) addressing long-term follow-up (LTFU) systems;
- (6) enhancing collaborative activities (within RC structures, among providers, with advocates, state systems, and insurers); and
- (7) developing methods for ensuring sustainability.

#### Shaping the Infrastructure of Health Care

Regarding ways in which the RCs and the NCC could influence the infrastructure of health care, survey respondents noted the importance of: (1) directly addressing insurance and reimbursement processes; (2) improving the workforce at multiple levels; (3) assisting NBS programs to adapt to changes in technology and practices; and (4), improving overall access to and utilization of technology.

## Potential Roles for NCC

When survey respondents were asked about potential roles for the NCC, three primary areas were identified: supporting organizational infrastructure; addressing educational needs; and creating systems change.

In terms of organizational infrastructure, respondents suggested that there is a continued need to:

- (1) improve communication within the NCC/RC network;
- (2) identify and take advantage of opportunities for collaboration between the RCs and national partners;
- (3) develop a robust evaluation for RCs and the NCC; and
- (4) identify additional funding sources.

The NCC was also seen as playing a critical role in education, particularly educating public health programs about the importance of genomics and genetic services. Lastly, respondents felt the NCC could be a major initiator of systems change by: supporting informed legislation and policy; helping to shape the adaptiveness of the health care system; and helping to identify and address disparities in access to genetic service providers across the nation.

## **Targeted Areas**

In terms of specific areas needing more support, RCs identified: (1) staffing and administration; (2) cross-RC expansion of successful projects; (3) technical assistance and access to experts (e.g., in telegenetics, health insurance, IT); (4) communication; (5) collaboration (e.g., enabling staff of one RC to attend the meetings of other RCs); (6) assisting states to develop systems for short and long-term follow-up, as well as other types of infrastructure (e.g., IT); and (7), supporting activities leading to single-payer universal health care..

## **Changing Models of Delivery of Genetic Services**

During the group discussions on November 18th, participants noted that a number of emerging issues necessitate the development of innovative models of care delivery in the United States. These factors include: (1) changes in the general health care system; (2) ongoing disparity in access; (3) the need for better data, including data to provide evidence of best practices; (4) emerging developments in genetic services delivery, such as the need to transition adolescents and young adults with genetic conditions to adult care and to clarify the respective roles of geneticists and pediatricians in the medical home; and (5) growing financial constraints due to rises in insurance costs and limited funding. In order to address these issues, meeting participants felt that the provision of care needed to be better distributed across disciplines and provider types and that alternative methods for care delivery needed to be developed and implemented.

It was suggested that the RCs could play a number of roles in developing and piloting innovative models of care. These might include:

- (1) convening and collaborating (e.g., working with FQHCs, home visiting programs and health IT, facilitating adoption of new care models by providers, and networking at the state, regional, and national level to develop a critical mass of support for these new models);
- (2) educating (disseminating ideas, building awareness of alternative health delivery models, educating colleagues, incorporating new models into training curricula, and highlighting critical implementation issues);

- (3) outreach (attracting nurses and other providers into the delivery of genetic services, engaging consumers as lifelong designers and consumers of services);
- (4) researching/piloting models (testing new ideas, documenting barriers); and
- (5) identifying financial resources to sustain these models.

The NCC might focus its efforts in this area on:

- (1) building awareness of the changing health delivery system;
- (2) engaging a broad range of national and state partners (e.g., national nursing and physician organizations, Title V and other public health programs and systems);
- (3) coordinating NCC/RC activities and policies;
- (4) identifying content experts; and
- (5) educating colleagues.

The discussion group also identified the following eight crucial outcomes to be achieved through new models for delivering genetic services:

- (1) ensuring an adequate workforce;
- (2) incorporating genetic services and genetic information into the medical home throughout the lifespan;
- (3) documenting model effectiveness;
- (4) financing models of health care and care coordination;
- (5) fully integrating genetic services into broad public health service delivery;
- (6) easier and more varied access to services and providers in local communities;
- (7) provision of services by the appropriate providers; and
- (8) reduced loss to follow-up among patients.

Additional discussion focused on some of the potential activities that might be pursued in the first four areas listed above. On the topic of workforce development, two theme areas emerged. The first centered on advocacy (e.g., mobilizing consumers and advocates to develop loan forgiveness programs for genetics provider training), education, and training (especially team-based training programs). The second theme concerned the need to review and pilot other models and approaches for providing specialty services (e.g., different triage methods for determining who needs genetic services and when they need them, as well as training programs for nurses and others to deliver genetic services).

In terms of incorporating genetic services and genetics information into the medical home throughout the lifespan, participants emphasized the need for: training and continuing education of non-genetics providers (with incentives to encourage participation); development and implementation of collaborative care models involving specialists and primary care (including better definition of the role of the geneticist in the medical home); and development and dissemination of family history and decision support tools.

Documentation of model effectiveness was the third focus area. To accomplish this, participants felt it was important to: pilot different models of care delivery; assess them for effectiveness and sustainability; and advocate for adoption of successful models into routine practice (NCC has a role in marketing, developing strategies for adoption, and engaging partners).

Regarding the final area of discussion, the importance of adequate financing for models of care, meeting participants felt that further work is needed to: track successful reimbursement practices; track reductions in long-term costs; educate different providers about the importance of adopting new models; and explore innovative methods of financing through public/private partnerships. The information collected through these efforts would provide data to support HRSA’s policy decisions related to financing. It would also provide the RCs with data to strengthen their ability to explore innovative public/private partnerships and other unique methods of financing clinical services.

### **Improving the Delivery of Genetic Services: Summary of Areas Needing Further Support**

Upon review of the material gathered from the NCC/RC survey as well as the discussions held among stakeholders over the past few months, the following domains (in bold) and themes are recommended as areas needing further support in order to improve the delivery of genetic services:

<b>Services over the Life Course</b>	<b>Improving Quality of Care</b>	<b>Collaboration</b>	<b>Education</b>
Prenatal Care	Quality Improvement	Engaging Consumers	Educating the Public
Newborn Screening	Quality Assurance	Engaging Public Health	Educating Families
Long-Term Follow-Up	Electronic Health Records	Engaging Social Services	Educating Providers
	Central Database of	Engaging Powerbrokers	
<b>Targeting Specific Areas</b>	<b>Enhancing Infrastructure</b>	<b>Improving Access to Care</b>	
Health Care Reform	Ensuring appropriate supports for the RCs and NCC to carry out their work	New Models of Care	
Workforce Improvement	Sustainability		
Emergency Preparedness	Standardizing Care		
	Supporting New Research		

Most of these priority areas<sup>2</sup> were the focus of small group discussion during the November 18th meeting. Regions were split into two groups (each group had a representative from each RC and the NCC), and participants were asked to: 1) vote on those areas that Project Directors and Project Managers saw as priorities in their region; and 2) once these priorities had been established, determine a level of funding that should be allocated to each area. Upon review of these small-group discussions, it was noted that:

- While one group selected a broad range of priority areas, the other group focused on only a few. *It was clear that each group, although comprised of a fair representation of the NCC/RC system, did not always agree on what should be priorities for the NCC/RC system. Areas of greatest agreement included: focusing on the life course; addressing access to care issues; improving the workforce; and creating new models of care.*
- Some priority areas received two or fewer votes within a break-out group. These included prenatal, education, newborn screening, emergency preparedness, electronic health records, collaboration, databases

<sup>2</sup> Topic areas discussed include: Prenatal, NBS, LTFU, Education, Emergency Preparedness, Electronic Health Records, Access to Care, Collaboration, Databases of Diseases, Life Course, Standardization of Care, Safety Net Providers, Creative Care Delivery, Healthcare Reform, Workforce Improvement, Engaging Consumers and Powerbrokers, Quality Assurance, and Quality Improvement

of diseases, safety-net providers, health care reform, and engaging consumers and powerbrokers. *This indicates that there continues to be considerable variation among the regions on which activities they see as most important for improving genetic services. This makes developing a national approach and national priorities challenging, particularly if there is a difference between HRSA and the RCs in terms of which priority areas are most critical to address.*

- In the second part of the exercise, participants allocated a limited virtual budget among priority areas for their region. In allocating their funds, it was notable that a number of topics selected as priorities during the first part of the exercise were not allocated any funding by participants in the second part. *It will be important for HRSA to remember this dynamic as it seeks to balance the need to be flexible (funding a range of priorities) with the need to ensure that sufficient resources are allocated to those priority areas it considers most critical. In carrying out their work, RCs are regularly faced with the challenges of a limited budget and so may need to remove from or limit funding to some important areas (which may or may not coincide with HRSA's national interests) in order to better support areas they perceive to be of the greatest need or with the biggest potential impact for their region.*

## **NCC and RC Suggestions for Improving Collaboration**

As HRSA, the NCC, the RCs, and their partners move forward in their efforts to expand and strengthen the delivery of genetic services across the life course, they will need to address some of the core challenges that have arisen and consider ways to improve their collaboration. To this end, survey respondents and meeting participants offered a number of suggestions.

### **Improve Communication**

Greater clarity is needed concerning: the roles, activities, and funding for the RCs and NCC; the staff roles and administrative structure of the NCC; and the relationship between RC and NCC priorities. One stakeholder noted that it may be helpful to have the same project officer assigned to the NCC and the RCs. Stakeholders also suggested: (1) including NCC activities in the activities matrices; (2) disseminating the NCC work plan/budget to the RCs; (3) providing incentives for collaboration between NCC and the RCs; and (4) creating opportunities for greater involvement of the RCs in the NCC. Strong interest was expressed in creating a committee, comprised of RC and NCC representatives, that would meet annually (at a minimum) to identify and further enhance opportunities for collaboration across the NCC and RC network.

### **Improve Integration**

Participants identified the need for better integration of HRSA's programs and funding streams and clear communication and alignment of national and regional priorities. It will be particularly important to have these priorities reflected in the grant guidances and national performance measures for the RCs and the NCC.

### **Improve Funding Disbursement**

Meeting participants recommended that funding should be long-term, sufficient to carry out the tasks that HRSA wants accomplished, and reflective of the costs of the administrative infrastructure needed to carry out the work. Grant guidances should encourage, or perhaps even require, participation by a broad array of stakeholders, particularly consumer groups and public health leadership. Supplemental funding opportunities, if available, were generally viewed positively, since they allowed for opportunities to create change in targeted areas. On the other hand, priority funding arrangements were found to be less helpful; they were seen as adding another layer of complexity to the oversight process and as promoting competition among regions. If priority funding is offered,

stakeholders recommended that: all regions have access to these funds; priority funding periods be shortened, with funds redistributed if priority projects are not as productive as anticipated; and funding be dependent on the applicant's demonstrated commitment to involving other RCs. Participants strongly expressed the hope that HRSA would avoid funding opportunities that promote competition among the RCs or between the RCs and the NCC.

## Guiding Recommendations for the Future

Based on the information from the survey and the November 18th discussion, the following issue areas are recommended for further consideration by HRSA staff:

- It is recommended that HRSA seek answers to the following questions:
  - From a national perspective, what activities are most likely to lead to improvements in genetic services across the life course?
  - How should national priorities be defined and will all regions be required to focus on these priorities?
  - How do these national priorities compare with regional priorities?
  - Are there priority areas that do not necessarily need to be funded by all regions, but could be targeted by one or two; if so, in what areas would it be helpful to have only a few regions engage?

When setting national priorities for the RCs and the NCC, it was suggested that HRSA consider the areas upon which regions can have significant influence versus those upon which the RCs' influence is limited. HRSA should consider the impact of different approaches adopted by the RCs (e.g., some may be highly focused on a grass-roots approach and others may follow a more structured, top-down approach) and determine whether certain approaches would be best suited to certain priority areas. Lastly, as it determines its future priorities and actions, HRSA should pay particular attention to the challenges identified by the NCC and RCs.

- Participants also felt that HRSA needs to ask whether its new focus areas will cause disruption in current activities. If so, what are the implications? For example, are there current projects that are in danger of being discontinued due to lack of funding or potential shifts in federal priorities? This list of priority areas needs to be clearly defined and strategies identified to ensure that gains made in the last seven years of RC funding are not lost.
- It may be helpful for HRSA to invest in developing a communications plan and to bring in outside experts to review current communication protocols and offer recommendations on how to improve communication among HRSA, NCC, and the RCs. It will be critical to clarify how each of these entities should be communicating with the others and how their respective educational activities could fit into a broader educational campaign for the public and providers.
- The NCC and several RCs noted that they have sometimes found it challenging to find and/or support appropriate staff to address certain areas. Expanding the use of "traveling experts" (as has been done in the past for medical home, communications, and emergency preparedness) may be helpful in meeting this

challenge. A review should be conducted to determine whether these traveling experts have provided sufficient support to the RCs to bring about the changes needed at the regional level or whether more national or regional staffing support is needed.

### **Considerations**

It may be helpful for future Genetic Services Branch guidances to include a “menu” of objectives for RCs to work towards, with specific instructions on which objectives need to be met by all regions and which objectives need to be met only by those regions that find them relevant. Overall, funding should be structured so that collaboration across RCs is encouraged and at least one RC is addressing each GSB priority. HRSA should consider funding different RCs (or groups of RCs) to develop, pilot, and evaluate different, innovative models of care and so avoid duplication of effort. As a part of this process, it will be important for the Genetic Services Branch to clarify its role in implementing and evaluating pilot projects that promise to have national significance. It will also be crucial to evaluate promising programs or models developed by the RCs to ensure fidelity when they are disseminated and/or replicated. Finally, HRSA must keep in mind the complexity of factors shaping priorities, activities, and challenges at the regional and state levels. As one survey respondent noted, ultimately the specific activities undertaken “will depend on when particular outcomes will be addressed, whether other states or regions have completed similar activities, what strategies the stakeholders recommend, what resources can be contributed by the states in our region, and whether we can build on national efforts.”

## Appendix A

### Survey of NCC and RC Staff

# HRSA Genetics Collaboratives Feedback Survey

## November 2010

Please indicate the regional collaborative you represent:

- Region 1—New England Genetics Collaborative
- Region 2—New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services
- Region 3—Southeast NBS & Genetics Collaborative
- Region 4—Region 4 Genetics Collaborative
- Region 5—Heartland Genetics and Newborn Screening Collaborative
- Region 6—Mountain States Genetics Regional Collaborative Center
- Region 7—Western States Genetics Services Collaborative

### Questions about Your Regional Collaborative (RC)

Please take a moment to reflect on the previous 7 years...

1. What have been your RCs biggest successes?
  - a. For each of the successes above, what steps has your RC taken to ensure sustainability? Which of these was most successful?
  - b. What steps does your RC hope to take to move these successes forward? (E.g. continued funding, moving to National Coordinating Center (NCC)/nationalize, activity has become self-sustaining.)
2. What are the top **two or three** biggest challenges or failures that your RC has had over the past 7 years?
  - a. For each challenge or failure, what were the **one to two** most significant barriers to achieving the goal or objective?
3. Were there any activities that your RC did not engage in that you would have liked to? Please describe.
4. How might future funding/changed direction/infrastructure help your RC address items identified in 2) and 3) above?
5. What new linkages would your RC like to establish with other organizations that would help your RC be more effective in achieving its mission (at the state, regional, or national level)?
6. Please describe what you feel should be the major outcomes of your collaborative for the next 10 years:
  - a. What **NEW** activities are integral to achieving these outcomes?

- b. Please describe what existing activities your RC believes should be a PRIORITY for your region for the next 10 years:
- c. In thinking about the genetic and newborn screening service needs for your region as well as the major outcomes to be addressed by your collaborative in the years to come, are there any gaps between the needs that you see and the services that your collaborative will be able to provide? Please describe.

### **Questions about the collaborative work between the RCs, NCC, and HRSA**

1. Please describe what your RC feels should be the major outcomes of the collaborative work between the RCs, NCC, and HRSA for the next 10 years:
  - a. What NEW activities are integral to achieving these outcomes?
  - b. Please describe what existing activities your RC believes should be a PRIORITY for the collaborative work between the RCs, NCC, and HRSA for the next 10 years:
2. HRSA has identified four major theme areas of focus in the years ahead: delivering genetic services via a life course approach, meeting state public health needs, improving genetic literacy of the public, and improving genetic literacy of providers.
  - a. What does your RC see as the role of the RCs and NCC in collaboratively addressing each of these areas of focus?
  - b. To address each of these areas of focus, what specific kinds of activities could be undertaken by the RCs and NCC collaboratively?
3. Please comment on how you feel the HRSA Genetics Collaboratives should be structured and funded (e.g. base and priority funding). What worked in the past? What did not? Should there be any changes or re-arrangements to the current infrastructure?
4. Please comment on how you feel the National Coordinating Center should be structured and funded. What worked in the past? What did not? Should there be any changes or re-arrangements to the current infrastructure?

Any other observations you'd like to share:

## **Appendix B**

### **Summary of NCC / RC Survey Findings**

# RC and NCC Survey Responses: Core Themes, Considerations and Recommendations

January, 2011

*Results compiled by Peter Antal, Ph.D.*

*Institute on Disability, UNH*

The bullet points included in this document were drawn from the results of a survey, conducted in November, 2010, of all seven regional collaboratives and the NCC. The results are one part of a multi-stage process to collect feedback from HRSA's partners to guide HRSA's strategic planning efforts. Of note, it should not be inferred that all entities (or even most) share the same perspectives and concerns (though this may come out in future discussion).

## **Contents**

Successes of the Regional Collaboratives and the NCC (Q1) .....	1
Achieving Sustainability (Q1a and Q1b).....	1
Identified Challenges (Q2 and Q2a) .....	2
New Linkages with Other Organizations (Regional Q5).....	4
What outcomes and activities should be pursued in the next 10 years at the regional level (Q3, Q6, Q6a, Q6b, Q6c)?.....	5
What outcomes and activities should be pursued in the next 10 years by the NCC? .....	7
What outcomes and activities should be pursued in the next 10 years at the national level by the RCs and the NCC (National Qs 1, 1a, 1b)?.....	8
Implications for HRSA's theme areas. What are the roles of the RCs and NCC in collaboratively addressing these areas? (National Qs 2 and 2b) .....	9
Recommendations for Structure / Funding .....	11
Other Thoughts .....	12
Potential Questions.....	13

## Successes of the Regional Collaboratives and the NCC (Q1)

### RCs

Core themes focused on:

- **Building infrastructure**
  - Organizational structure, website improvements, improved communication methods
  - Volunteer mobilization
  - Building collaborative relationships (working partnerships across labs, across states, diverse stakeholders)
  - Creating opportunities to share best practices and lessons learned
  - Developing leadership
- **Development of resources impacting the care process**
  - Provision of educational / service resources
  - Patient care tools (diagnostic guidelines, a range of patient and provider resources, documenting best practice for long-term care)
- **Publications**
- **Supporting innovative projects**
- **Emergency preparedness**
- **Newborn screening**
- **Long Term follow up**
- **Transition**
- **Consumer training**
- **Provider training**
- **Data gathering** (needs assessments, documentation of best practice)
- **Improved screening, diagnosis, and clinical care**
- **Sustainability for a number of current projects via identification of new grant funds**

### NCC

- **Building infrastructure**
  - Organizational structure, website improvements
  - Building collaborative relationships (HRSA, MCHB, GSB, ACMG, RCs)
  - Reduce duplication of costs through multi-region activities
- **Creating venues for cross-RC work**
- **Program evaluation**
- **Supporting multi-region activities**

## Achieving Sustainability (Q1a and Q1b)

### RCs

While future funding was identified by most respondents, a range of additional steps have been taken as well. These include:

- **Strengthening core approach**
  - Strategic planning
  - Collaboration (the importance of establishing friendly and trusting relationships)

- within the region: buy-in from other groups (professional organizations, private companies, state newborn screening programs, advisory council, etc)
    - identify opportunities for cross-regional collaboration
    - participation in national efforts
  - Utilization of international experts to develop/implement best practices
  - Collecting data
    - to advocate for improved reimbursement for genetic services
    - to document best practices
- **Adopting a range of dissemination efforts**
  - Publications / presentations on work
  - Dynamic use of web (to share a range of media, utilize free resources like Google Maps)
  - Sponsoring training (for professionals, consumers)
  - Participation on national workgroups / use of national networks to share products
- **Providing support**
  - Funding for travel
  - Providing technical assistance
  - Updating products to reflect changes in information and systems
  - Leveraging with other groups to provide funding support
- **Creation of sustainable practices:**
  - Integrating efforts into existing resources (eg. working with public health, incorporating into Title V budgets, etc.)
    - "...as the best practices and information are incorporated into public health and clinical practice, these will help sustain the outcomes of the activities. The Collaborative partners need to find value in what is being done to put forth efforts to sustain the activity without federal funding."
  - Going national (finding new funding sources to expand)

## NCC

Discussed the critical nature of funding for many core activities. Noted however that workgroups might continue as these are staffed through individual volunteers. Additionally noted:

- **Creation of sustainable practices:**
  - Noted the importance of developing and identifying new grant opportunities
  - Engaging industry to develop and sustain tools
  - take advantage of national partnerships to advance newborn screening
- **Adopting a range of dissemination efforts**
  - Sponsoring national workgroups

## Identified Challenges (Q2 and Q2a)

### RC Challenges

Challenge areas identified include:

- **Individual Challenges**
  - Engaging families/advocates
  - Time availability of volunteers
  - Identifying committed and engaged leadership
- **State Level Challenges**

- Challenges in developing state genetic plans (seed-funding only goes so far)
- Engaging other organizations
  - Participation in MCH block grant funding allocation of state Title V programs
    - understanding of Title V professionals ("Title V needs assessments and plans seem to be constructed to define the situation as it is rather than to redirect programs to better meet needs")
  - Engaging state NBS programs
- State budgets and policies reducing ability of partner travel
- Ability to be responsive to state public health needs: "charges from HRSA do not always align with the authority held by RC or the funding received through the cooperative agreement; RC can't always be responsive to state public health needs"
- Weak state systems for NBS, lack of a formalized relationship within state programs (focus on initiating programs have had a negative impact on systems improvement),
- **Regional Challenges**
  - Representation
    - Full representation of all relevant partners: "When the RC focuses on areas of little interest to certain stakeholders, these stakeholders are less likely to participate in RC activities."
    - Full representation of all states
    - Challenge of finding rural representation in the determination of national priorities (e.g., there is a lack of internet access in many areas but this is often relied on as one of the priority solutions)
  - How to coordinate all projects with the region
  - Financial
    - Large geographic area coverage and higher travel / phone costs
    - Priority funding arrangements and impact on coordination / collaboration with other activities
    - Lack of resources to support data entry / tracking
  - Dissemination
    - Need for experience in manuscript writing vs. cultural emphasis on work
  - Need for greater technical assistance
    - Improving communication
    - Implementation of products / adapting to recommended activities
  - How to move things to national level work
- **National**
  - Communication and coordination across RCs, NCC, HRSA, other pertinent organizations
  - Financial
    - Financing the health care system
      - Lack of single payer universal health care
        - Lack of "reimbursement for medical home activities, genetic counseling, education and outreach; many med facilitates have no experience with medical home codes and/or their contracts with health insurers do not include those codes (no way to sustain MH activities)"
      - Clinic funding
      - Data entry funding
    - Lack of resources to sustain important initiatives (ask the geneticist)

- Lack of funding for new projects (or to support priority areas without dedicated funding)

## NCC Challenges

- **Clarification of Roles**
  - How others perceive the NCC
    - Misunderstanding of NCC role and funding mechanisms
    - Unclear mission from HRSA about what NCC should be doing and how to inform the RCs
    - Public criticism of the NCC
  - Perspectives on the RCs
    - Unknown what education and policy needs of RCs are
- **Communication Challenges**
  - Geographic distance among RCs
  - Website limitations
  - Failing to maintain bi-directional linkages between groups
- **How / When / Who should Nationalize...**
  - "RCs have been reluctant to give up control of some projects, even when those projects became 'national'"
- **Need for Improved Collaboration Between RCs and NCC**
  - Lack of trust between some RCs and NCC
  - Funding scenarios implemented which create conflict between these entities
    - There is a corresponding lack of financial incentives to encourage collaboration

## New Linkages with Other Organizations (Regional Q5)

### RCs

- **National level**
  - Have a better understanding of MCHB priorities
  - Other HRSA programs
  - Other national groups / federal partners (CDC, AHRQ, Robert Wood Johnson, NBSTRN, GA, NCHPEG)
  - Creation of a parallel HRSA resource to the Research Portfolio Online Reporting Tools
- **Regional / State level**
  - PCP/Pediatrician communities
  - Special educators
  - Professionals (medical students, genetic counselors, social workers, dieticians, LEND programs)
  - Schools of public health
  - State Medicaid programs
  - State NBS programs
  - Third party payers
  - Family to family organizations
  - Library systems

### NCC

- Better linked to Departments of Special Child Health Needs. other national centers
- Other major initiatives for Children and Youth with Special Health Care Needs

- Coordination with other HRSA centers (safety net providers, consumer organizations, AMCHP, Family to Family organizations) and the NSGC
- Help RCs become connected
- Formalize relationships through memoranda of understanding

## What outcomes and activities should be pursued in the next 10 years at the regional level (Q3, Q6, Q6a, Q6b, Q6c)?

### RCs

Most see value in continuing current activities over the next 10 years (e.g. focus on quality assurance, quality improvement, long-term follow-up, medical home, transition, education, collaboration building), with an added emphasis on expanding services (number served, different populations, additional geographies, nationalization). Other areas include:

- **Research to Practice**
  - Generation of new knowledge / research
  - Collect data and strategies, evaluate services, document evaluation for specific diagnoses and treatments
    - Facilitated data collection and analysis / data integration: "In particular, we see a need to improve data linkages between states' programs, clinical research studies, long-term management, etc., to fully chart the health of screen-positive newborns over their life course. Such data infrastructures will be crucial to informing future guidelines aimed at improving clinical management of these disorders. "
      - e.g. information exchange, family health history tool
    - Development of evidence based protocols
  - Integration of best practice activities into health care systems
    - Application of innovative practice patterns via targeted academic detailing
- **Shaping the Infrastructure of Health Care**
  - Insurance and reimbursement: Enhancing linkages with private third party payers to improve reimbursement for genetic services. Dialogue with health insurers and strategies for appropriate payment.
    - Documenting effectiveness of care provided by genetic specialists to improve reimbursement for clinical genetic services and demonstrate benefits of specialty care for people with genetic conditions
    - Telemedicine barriers and solutions and billing, noting cross-state implications for all
    - Single payer universal health care (question about how best to address the system from an insurance standpoint)
    - Coverage provided for education, services, supplies
  - Workforce improvement: Providing workforce development in the area of genetics by promoting the specialty as a growing area of interest and enhancing educational efforts
    - Scholarships for genetic counselors
    - Service models pairing nurse practitioners and genetic counselors
    - Training opportunities for genetic professionals
    - Developing programs to interest students in genomics and genetics in order to increase genetic specialists in practice

- Adaptation
  - Match advancements in newborn screening: What is the role of RCs in assisting NBS programs with expertise for expanding NBS (e.g. SCID)? What are the implications for the provider base?
- Improving access and utilization of technology
  - Improving IT infrastructure
- **Developing Regional Approaches to Delivery of Care / Creation of Systems of Care**
  - Education
    - Partnering with genomics centers and national genomics efforts to educate families and providers about genetics and personal health
    - Provide greater education for providers and consumers
      - coordinated effort to address direct-to-consumer genetic testing and marketing
      - promoting family health history
    - Culturally appropriate educational campaigns
    - Community outreach and education
  - Communication improvements
    - Communication among providers
  - Collaboration
    - Increased collaboration within RC organizational structures and providing better ongoing support to work groups (loss of support to some groups has led to group dissolution and, subsequently, a loss of perspectives that were critical for the larger group)
    - Increased collaboration among providers, public health (particularly community health care centers, other public health groups), consumer organizations, clients, insurers
      - involve more specialties, not just geneticists, need to engage medical professionals
    - Increased civic engagement, participation of family advocates
      - training for parents to facilitate care coordination
    - Engage state systems to develop models around access to care
    - Engage health insurers
      - financing of genetic services
        - health insurance payments for appropriate services (diagnostics, foods, care, transition health insurance coverage, medical home)
    - Share best practice models
    - Link with national initiatives
    - Work with NCC to promote technical assistance, support communication
  - Improved access to care
    - Addressing disparity (in access as well as health outcomes)
    - Engaging constituency about IT, health insurance, medical home
    - Telemedicine
    - Increase access to information and systems
  - LTFU: "we see a significant role for strengthening both state laboratory performance and the downstream processes that occur after newborn screening, namely LTFU, identification of a medical home, improved management, and transition care from pediatrics to adolescence and adulthood."
  - Emergency preparedness
  - Transition

- Medical home
- Quality Improvement
- Identification of mechanisms for sustaining regional collaborations

One respondent noted that ultimately, the specific activities undertaken "will depend on when particular outcomes will be addressed, whether other states or regions have completed similar activities, what strategies the stakeholders recommend, what resources can be contributed by the states in our region, and whether we can build on national efforts. "

## What outcomes and activities should be pursued in the next 10 years by the NCC?

- **Organizational Infrastructure**

- Enhanced communication infrastructure
  - Supporting RCs to find tools
  - Link related local organizations to RC activities
  - Support publication and presentation of RC and NCC work
- Enhanced collaboration
  - Tie efforts to HRSA/MCHB/GSB plan
  - Support taking RC successes to a national level
  - Increased outreach to professional organizations and advocacy groups
    - greater involvement with safety net providers (community health centers, migrant health centers, state implementation grantees), education of nongenetic-trained providers (PCPs, allied health professionals)
    - building bridges among providers
    - development of interagency agreements or through DHHS
- More robust evaluation for RCs and NCC
- Identify additional funding resources for NCC and RCs
- Creation of MOUs/MOAs

- **General Education**

- Helping clarify genomics and genetic services in public health (quality, access to services)
  - Integration of genetics messages into national public health messages
- Activities aimed at increasing the knowledge and competence of non-genetics health care providers
- Educate legislators

- **Topical Focus**

- Active involvement in financing issues
  - Need to work with national advocacy organizations to improve reimbursement and represent people with genetic conditions better in health care reform
  - Collaborate with HRSA's national center on insurance and financing
  - Activities aimed at improving financing and reimbursement for genetics services
- Workforce
  - Activities aimed at increasing the genetics workforce (not only MDs and genetic counselors, but specialized nurses)

- **Systems Change**

- Support informed legislation and policy
  - Educating policy makers as to where tax dollars are going, having role as policy is crafted

- Improving adaptiveness of system, particularly in regards to:
  - Rapid changes in scientific developments
  - New paradigms for delivery models
  - Consumer control of information
- Address maldistribution of traditional genetic service providers

## **What outcomes and activities should be pursued in the next 10 years at the national level by the RCs and the NCC (National Qs 1, 1a, 1b)?**

Within the overall context of improving health outcomes:

- **Improve Infrastructure Across NCC and RCs**
  - Communication
    - Open minutes from all groups, improved collaboration with NCC
    - Address communication issues across RCs, NBS, NCC, other HRSA activities, and other national groups
  - Coordination
    - "The NCC needs to review the RCs proposals to see what programs/projects are happening and where RCs could partner or support initiatives"
    - Identify liaisons for other HRSA funded activities (State Title V, CSHCN programs, division staff, national centers, bureaus of primary care, community health centers programs)
    - Look at how projects are developed across regions to avoid duplication
  - Collaboration
    - Improve interactions between NCC and RCs
    - Develop a national evaluation plan
    - Improve state level infrastructure to enhance capacity of states to move forward
    - Support technical assistance to RCs
    - Nationalization of RC projects (LTFU, ACT sheets)
- **General Areas of Improvement**
  - Continue supporting core projects: improving LTFU, access to care, transition, medical home, quality improvement work (linking best practices and improved outcomes)
  - Continue supporting new research
  - Public education
    - Improve public understanding
    - Education of primary care providers
  - Standardization of services
  - Address disparities in health
  - Improve process of health care delivery
  - Workforce improvement
    - Address lack of diversity in genetics workforce
- **Targeted Areas of Improvement**
  - Documentation
    - Identify gaps in need versus available resources and services
    - Identify gaps in workforce
    - Pool data across multiple sources

- Point-of-care decision support tools (also for non-genetic providers)
- Telemedicine
- Linking electronic medical record and NBS systems
- Address financing and reimbursement challenges
  - Implications of health reform on genetics and NBS follow up
  - Conduct research on insurance reform
  - Conduct research on changing patterns of insurance coverage

## Implications for HRSA's theme areas. What are the roles of the RCs and NCC in collaboratively addressing these areas? (National Qs 2 and 2b)

- **Prior to launching any a new initiative, it will be important to:**
  - Clearly define lifespan issues (incorporate patients, parents and providers)
  - Frame link between education and health outcomes
  - Clarify needs that will be addressed
  - Reduce duplicative work and prioritize resources
  - Understand potential impact to existing priorities if new work is funded (particularly where current work supports these theme areas)
- **Range of Possibilities**
  - Regions see roles in many of these areas. It is important to note that a number of activities already underway fit into these theme areas (though not across all regions).
  - General
    - Need enhanced NCC role in coordination and facilitation
    - Explore public/private partnerships
    - Improvement of information systems
    - Pursue greater collaborations with Genetic Alliance and NCHPEG
    - Note that work around medical home, transition, and LTFU cuts across all four areas
    - The RCs should determine and prioritize activities within the focus areas of HRSA using assessments of its stakeholders
  - Life course approach
    - Emphasis on medical home and transition
    - Ensure a body of trained and available providers by educating and encouraging people to enter the professions
    - Ensure that payment is available for these services
    - Ensure that people know how to access services
    - This will require regional networking as well as taking advantage of the NCC's role in developing registries, providing CMEs and maintenance of certification assistance.
    - Public service announcements, presentations within schools at every level about genetics, health and the opportunities available in the many fields serving PSHCNs
    - Working with insurers to understand the benefits to their business by appropriately covering necessary services
    - Better and more coordinated directories of needed services (see [www.Cap4kids.org](http://www.Cap4kids.org))
    - Improve coverage and reimbursement for genetic evaluation and counseling so that individuals can take advantage of genetics throughout the life course

- Meeting state public health needs
  - Expand capacity for health information exchange
  - Address role of state public health programs
  - Continue specialty training of state public health professionals in NBS and genetics
  - Provide a forum for genetic service providers to meet and collaborate among themselves and with public health professionals
  - Facilitate discussion of the issues to create a consensus of the vision of the RCs for public health needs
  - RCs must identify state needs and relay that information to federal/national partners
  - Campaigns to encourage the interests of young adults in NBS and genetics
  - Organize face-to-face and virtual meetings and seminars to provide a forum for genetic service providers to meet and collaborate among themselves and with public health professionals
  - Facilitate discussion of the issues to create a consensus of the vision of the RCs for public health needs
  - Improve/expand the workforce
- Genetic literacy of the public
  - Culturally appropriate and accessible educational interventions
  - Promulgate educational materials that are at the appropriate literacy and cultural level for consumers
  - Integrate genetic information into all levels of the public school curriculum
  - Participate at the national level to develop and implement a “public service announcements” campaign
  - Use consumers telling their stories to make genetics real
  - Use NBS programs as entry points, collaborate with NCHPEG
  - RCs must work very, very closely with the Clearinghouse and NNSGRC in the development and dissemination of materials that fit our regions
  - Improve just-in-time screening, diagnosis and management information in various languages and reading levels
  - Work together to identify existing educational materials at all appropriate literacy and cultural levels for consumers
  - Work with curricula developers to integrating genetic information into the public school curriculum
  - Note that linkage back to local level is critical – education is a local effort
- Genetic literacy of providers
  - Training opportunities for health professionals
  - Training for mid-level trainees
  - Integrating genetic information into all level of the medical school and other professional training curricula
  - Ensure that recertification requirements for health professionals include modules on genetic diseases – work with professional associations and training organizations
  - Use consumers telling their stories in the curricula
  - Concern raised: "Genetics membership organizations are not championing the work of the NCC/RCs to the providers on the front line. "

Comment: "For all areas of focus, we believe the primary role of the NCC is to support communication between the seven RCs and among the RCs and other national organizations. The NCC should actively increase awareness about the collaboratives among national agencies and organizations and help facilitate collaboration with national groups. The NCC should track activities of the RCs and other national organizations and make this information accessible to all collaboratives. Making this information available would allow the RCs to identify potential partnerships. Finally, the NCC should facilitate expansion of RC activities by helping with dissemination of products and information, piloting activities, and identifying appropriate sources of additional funding."

Comment: " We see the need for increased emphasis on activities that pertain to medical home and transition. These topics cut across all four of the identified theme areas. Additionally, improving information systems for the collection and maintenance LTFU data will produce an evidence-based infrastructure to inform state programs, improve the literacy of providers and consumers and aid in the delivery of genetic services."

## **Recommendations for Structure / Funding RCs & NCC (Regional Q4)**

- **Need for greater unity in HRSA's approach**
  - Same project officer for NCC and RCs
  - Better integration of HRSA programs
  - Alignment of regional and national priorities
    - Align national evaluation criteria with regional goals
  - Focus funding on activities and clear expectations
- **RC and NCC Collaboration**
  - Include NCC/NBSTRN activities in activities matrix
  - Dissemination of NCC work plan/budget
  - Greater involvement of RCs at NCC; alter governance structure for NCC to have annual reps from one or two of the RCs
  - Provide incentives (merit based awards) for collaboration between NCC and RCs
    - Larger pool of money for NCC to distribute to RCs to develop projects of national significance
- **More Funding**
- **Resource Support for Targeted Areas**
  - Better utilization of limited experts
    - Identification of resource experts (telegentics, health insurance, IT, emergency preparedness)
    - Increased use of experts
  - Funding for communication
    - Support better communication among regions as well as with national
    - Funding for RC representatives to attend activities of other RCs to facilitate exchange of ideas
  - Support uniformity of state systems (Medicaid, private health insurance, IT standards, NBS screening and short/long-term follow-up)
  - Support for single payer universal health care
- **Concerns / Issues Raised**
  - While there is funding for start up, it would be helpful if there was a line of funding for continuation grants
  - Will HRSA's new focus areas cause disruption in current activities? If yes, to what extent?
  - Importance/helpfulness of supplemental funding to target unique opportunities for change

## RC Specific (National Q3)

- **General**
  - Needs to be better integration of HRSA funding streams and projects
  - Funding should be consistent, ensure participation by a broad array of stakeholders
  - Each RC should have a public health focus and involvement of public health leadership, as well as better linkages to state NBS programs
  - Improve funding levels to fit tasks: "The guidance should include a menu of objectives for RCs to work on; there should be collaboration across the RCs to ensure that at least one RC is addressing each objective, ensuring that each RC does not have to address them all."
  - When offering new funding, note potential implications of competition on cross-site collaboration
  - A 10-year commitment would be a substantial aid in mobilizing and planning for sustained change
- **Funding allocation, more support for**
  - Staffing needs
  - Cross-RC expansion
- **Priority funding**
  - Request for base funding and a top tier for priority funding
  - Another request for priority funding to be made available to all
  - Shorten priority funding with option to refund and distribute evenly
  - One lump funding line per RC rather than separate priority funding lines
  - Priority activities should be for shorter duration or restricted based on ability or inability to involve other RCs
- **Supplemental funding**
  - Creates opportunities to make changes in targeted areas that may otherwise not be possible
- **Reporting**
  - Align performance measures with national goals and funding of what RCs are doing

## NCC Specific (National Q4)

- **Clarify**
  - Roles, activities, funding streams of various partners
  - NCC staff roles and administrative structure
  - How RC priorities relate to other NCC priorities
  - Issue of competition between NCC, RCs and HRSA
- **Focus on**
  - Ensuring sufficient funding for NCC administration
  - Providing technical assistance on how to develop an effective and efficient collaborative
  - Coordinating activities across RCs to reduce duplication;
  - Assisting in meeting HRSA's major themes of focus

## Other Thoughts

- Longer time periods to respond to 'short' surveys!

## Potential Questions

### Instructions for the Planning Team

Prioritize questions that are most important and can be dealt with via open discussion (whole or break out). What questions are most important to ask now that will help the group focus on areas that need greater support and how the infrastructure should operate? Please rank them from 1 (Critically Important and Timely); 2 (Somewhat important, can be addressed in future discussions); 3 (Not critical to address in this forum).

*Questions for Michele to possibly address as part of her presentation:*

- What should define a national priority? How does this compare with regional priorities? Are there national priorities that all groups can agree on?
- Thoughts about different funding strategies (e.g. priority funding, supplemental) and their impact on creating opportunities for conflict / collaboration among partners?
- In seeking to follow along the four new priority areas, to what extent will this represent an expansion or replacement of funding priorities during the next grant cycle?

*Recommended for Full Group Discussion on the 18th*

1. To what extent should the RCs be focused primarily on systems development (including technology development) vs. service delivery vs. training? What is the overall logic model of change guiding the work of HRSA, NCC and RCs which clarifies roles of each group, and how, when and why they should connect? What are the short and long-term outcomes? Who should support funding or other resources for training? for legislation? for addressing the financial aspects of the system? for developing and maintaining a state public health infrastructure (e.g. funding stream for development of state-level public health genetics staff)? (by itself, this can be broken up into a series of discussions around specific goal areas that would take up the whole afternoon - PA)
2. Expand on the notion of system adaptation and its importance to quality care. How can the NCC and RCs work together to improve the adaptiveness of the system? What are the needed areas of focus?

*Recommended for Future Conversations*

1. Work out a transition arrangement for when RC work goes national and what the NCC could / should do as a part of this process. What is it the NCC can offer? What is the concern? Is the problem that there haven't been enough projects ready to go national? or that RCs don't understand what the NCC can offer or don't see a benefit to collaborating with them? others?
2. National sharing of experts – what field areas can be best supported by the traveling expert model? What should their roles be with each RC?
3. Several regions noted the challenge of reimbursement rates for services and how to fund services in general so that improvements can be sustained. Might be helpful to outline the potential roles for the NCC and RCs in this area and create a series of action steps (for both this year and future years).
4. Discussion on general perspectives of the NCC - mission, roles, collaboration vs. divisiveness. Address the perception that a funding relationship between the NCC and RCs would create an incentive for collaboration and follow-up that does not exist. What are the other implications of funding flowing from this resource?
5. Which current projects are in danger of being lost due to lack of funding in future years or potential shifts in federal priorities (we may need a needs assessment of implications of funding changes to promising practices)? Are there any solutions to this issue?

*For Discussion Re: Process*

1. Maybe use a break-out for separate NCC / RC discussions to clarify issues around collaboration and then have them get back together to figure out solutions?

2. Maybe have an exercise where we list out major domain areas of focus (e.g. training, service provision, public education, infrastructure development, etc.) and ask each member to vote with a limited dollar sign sticker to indicate which areas should get priority in future funding rounds?
3. Allow for any open discussion?
4. As a future idea, it may be helpful to have a listing of all the regional level challenges and what each region did to address it (that way regions that come across similar problems could have some potentially workable ideas)