

New England Genetics Collaborative

Annual Meeting, December 2010

Meeting Summary

By: Peter Antal, Ph.D.

Institute on Disability, University of New Hampshire

February, 2011

I. Introduction

This report provides a summary of the New England Genetics Collaborative (NEGC) annual meeting held December 1, 2010 in Portsmouth, New Hampshire. The annual meeting is considered an opportunity to work with regional partners to inform and conduct an in-depth work plan review. In addition, the meeting serves as a chance to update partners on issues of current interest, and engage organizations who might not be familiar with the day to day work of the NEGC. This summary includes highlights of the meeting (p.1), feedback provided via evaluation forms and group discussions (pg.11), and recommendations (pg.16).

Sixty-five individuals participated in the meeting. Project staff highlighted the key accomplishments of the project over the course of the past year (success in 90% of 64 project objectives, launching of the learning collaborative, refinement of the tool for special educators, new fact sheets on genetic conditions, and legislation in Maine enabling LTFU systems), and highlighted major activities to be undertaken for next year (including implementation of a data registry for quality improvement, continued refinement of marker analysis in lab testing, implementation of the learning collaborative, moving the special educator tool to the web, and holding an Emergency Preparedness symposium). Breakout sessions on how to effectively engage with genetic counselors, families, and the New England Birth Defects Consortium were held. In addition, open workgroup meetings were held that enabled cross group and new stakeholder participation in the activities of individual workgroups.

As with the previous year's event, we learned that most participants found the meeting helpful, that they had opportunities to share their perspectives, that they had a good understanding of what the NEGC will accomplish in Year 5, and that the NEGC is "headed in the right direction." More than half of responding participants felt that the work of the NEGC has resulted in tangible outcomes resulting in improvements in high quality genetic services in the region. In terms of recommendations, participants highlighted a range of groups that the NEGC staff could do additional outreach to, including major medical centers, school nurses, family advocate groups, March of Dimes, Save our Babies, Medicaid leadership and other major organizations (AAP, AFP, ACM, CCPCMH).

II. Meeting Highlights

During the meeting, participants heard an overview of the core mission and accomplishments of the NEGC, listened to important updates from our federal partners, heard a brief summary of laws guiding use and disclosure of genetic and newborn screening information, and participated in joint discussion sessions with genetic counselors, families, and members of the New England Birth Defects Consortium.

Sixty-five people participated, including a mix of physicians, specialty care providers, state coordinators, family members of consumers, advocates, and other service providers. In addition to the overview of the project and special discussion sessions, five of the project's workgroups held meetings as did the project's Advisory committee.

NEGC Update

Dr. John Moeschler presented on some of the core work of the NEGC during Project Year 3 and recent work in Year 4. Major points covered included: an overview of the mission and vision of the NEGC; shared efforts around national endeavors and committee participation; and highlights of the core work underway at the NEGC.

This included a focus on improving communication, developing meaningful partnerships, improving sustainability and growth, and creating systems change.

National Activities and Update by Sara Copeland, MD, HRSA/MCHB Genetic Services Branch, Judith Benkendorf, MS, CGC, National Coordinating Center, Amy Hoffman MPH, CCRA, Newborn Screening Translational Research Network

Sara Copeland, MD

Dr. Sara Copeland provided a brief overview of the Health Resources and Services Administration, including its vision and mission.

Vision: HRSA envisions optimal health for all, supported by a health care system that assures access to comprehensive culturally competent, quality care.

Mission: HRSA provides national leadership, program resources and services needed to improve access to culturally competent, quality health care.

This was followed by a brief summary of core outcome areas for children with special health care needs:

- Coordinated ongoing comprehensive care within a medical home
- Adequate private and/or public insurance to pay for the services they need
- Early and continuous screening
- Services organized in ways that families can use them easily
- Families partner in decision making at all levels, and will be satisfied with the services they receive
- Services necessary to make appropriate transitions to adult health care, work, and independence

Dr. Copeland then provided an overview of the major funded programs and the services that are supported. For example, the Heritable Disorders Program supports the regional collaboratives (RCs), effective newborn screening and follow up, the Newborn Screening Clearinghouse, and the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC). Special Projects of Regional and National Significance (SPRANS) supports a range of educational projects as well as treatment and care centers for hemophilia, and community projects focused on sickle cell and newborn screening. The Sickle Cell Disease Treatment Demonstration Program (SCDTP) supports sickle cell disease and treatment programs, including 9 networks and 1 coordinating center. This provides for comprehensive, evidence-based care for people living with sickle cell disease. Lastly, the Congenital Conditions program provides evidence based information and services to parents receiving a positive diagnosis for a prenatally or postnatally diagnosed condition.

New activities in 2010 and 2011 include: a focus on early and continuous screening through the medical home, supporting a family history project, a Genetics in Primary Care Training Institute, and a Sickle Cell Disease and Newborn Screening Program. Upcoming programs shared by Dr. Copeland included the Interagency Collaborative Committee on Newborn Screening and the NBS CQE Program (which will focus on enhancing the quality of NBS systems).

Dr. Copeland noted that the SACHDNC endorsed SCID to the recommended uniform screening panel (RUSP, approved by Secretary Sebelius), and supported: sickle trait carrier screening in athletes; the formation of a carrier screening task force; and the addition of CCCHD as part of the RUSP.

In looking forward, Dr. Copeland noted that they will continue to explore the issues of the maldistribution of all aspects of genetic service capacity, including many of the policy and education and training issues that will surround us. These issues include such areas as: family health history, emergency preparedness, education of providers and consumers, utilization of telegenetics/telehealth options.

Questions which arose...

- Q: What is the carriers screening passport project? A: Identify where there is agreement at the public health level and what is being done with the intent of developing an algorithm for what should be screened for when, why, and how.
 - Q: At what level should it be done? A: Not determined yet. This needs to be reviewed.

Judith Benkendorf, MS

Judith Benkendorf provided an overview of the NCC, including brief summaries of its three workgroups (medical home, ACT sheet, telegenetics) and other core activities (visiting professorships, cultural competence, and communication). The medical home work group supports RCs work around the medical home concept, and seeks to support enhanced linkages between genetic expertise and primary care providers. The ACT sheet workgroup supports the development of new ACT sheets, will begin some focused work with pediatricians and physicians around developmental disability algorithms, and will be analyzing ACT sheet utility. The telegenetics workgroup, currently being restructured and meeting in May 2011, will be submitting abstracts highlighting RC activities to national meetings. On the topic of visiting professorships, both Genetics and Medical Home Visiting Professorships have been awarded. Their multicultural work focused in part on a special satellite session on Native American Perspectives given the unique challenges of CPT1 variance that is specific to this population.

Question which arose...

- Is there a central definition of medical home? A: Yes, Dr. Carl Cooley noted that the current accepted definition is based on 2007 joint principles established by the AAP and AAFP (and tied into criteria of the NCQA)

Amy Hoffman, MPH

Amy Hoffman provided an overview (structure and goals) of the Newborn Screening Translational Research Network (NBSTRN).

The target audience is primarily for newborn screening researchers, but also collaboratives, state labs, clinicians, families, patients, brain disease consortia, advocacy, policy, and industry. There are four standing committees, largely staffed by volunteers (Clinical Centers, Lab Workgroup, Info Tech Workgroup, Bioethics and Legal), a lysosomal storage disorders subgroup and three disease specific workgroups (endocrine, hemoglobin, metabolic). Accomplishments in years 1 and 2 included formation of committees, a minimum data set, collection of newborn screening lab info, web development, IT infrastructure, and collaborations with APHL and Genetic Alliance. They also conducted a SCID and LSD pilot, and developed a subcontract with 5am Solutions for virtual reproduction of DBS. The virtual repository will be centralized, and web based. It will provide an inventory of DBS samples, allows browse and query, as well as tools to review and manage

requests. This will be a helpful resource for investigators, state programs, and NBSTRN membership. In the future, they plan on further clarifying needs, developing data dictionaries and LTFU language, create a bedside data capture tool and centralized database for LTFU data, model consent modules, pilot studies, create new repositories, address Bio-ethical issues, go after funding opportunities, and pursue sustainability.

Questions which arose...

- Q: Parent permission? A: Yes – depends on state
- Q: Available on NEGC website? A: Yes, it will be.
- Q: How long hold onto sample? A: NBSTRN does not hold onto, but provides an infrastructure for accessing the data based on individual state policies.
- Q: Gestational age included? A: When available.... Using weight as a surrogate when not available.
- Q: What states are currently involved? A: Current states: CA, IO, NY, MI, WA, WI. These do retain data for more than a year.

State Laws of New England: Use and disclosure of genetic and newborn screening information for the purposes of treatment, a registry, and research. - *Michelle Winchester, JD, UNH School of Law*

Due to time constraints, Michelle Winchester's presentation was cut short considerably. In the time available, she provided a brief overview of the purpose of her work, a few of her highlighted findings, and primary conclusions.

Purpose of the work: Determine whether New England state laws impose barriers or additional procedural requirements to the use or disclosure of genetic information, including newborn screening information, when the use or disclosure is for the purpose of treatment, a public health registry, a registry established as a health care operation, or research.

Ms. Winchester identified substantive differences in the framework established by HIPAA and how each state's legal framework handled disclosure, noting that consent requirements vary. Her primary conclusions for each of the question areas follow below:

Use/Disclosure Concerning Treatment

- HIPAA expressly allows the health care provider to disclose PHI for treatment without consent of the individual who is the subject of that information. Four out of six New England states neither expressly defer to federal requirements nor expressly address disclosure for treatment in laws concerning consent to disclosure by health care providers. No state law addresses disclosure for treatment, by the public health agency that is not a covered entity under the HIPAA privacy rule.
- Laws governing consent requirements for disclosure of genetic information vary among the states, adding a consent procedure step for three states. The states that require consent exclude disclosure of NBS information, although the exception is likely limited to program purposes and processes described in law.
- The NEGC should be attentive to the development of laws governing state health information exchanges to maximize benefit to health care provider access, as well as public health activity access.

Use/Disclosure Concerning Public Health Registry

- Likely insufficient commonality in current NBS policies and procedures across New England states to support a registry for the purposes listed. Additional support may be found in the broader general public health authority delegated under state law, although such an effort should be weighed carefully, with full consideration of the political and economic climate.
- Birth defect surveillance programs seem better suited to proposed registry purposes and state programs seem more, although not completely, aligned. Investigation into the integration of NBS programs with the surveillance programs may be worthwhile.

Use/Disclosure Concerning Health Care Operation

- While allowable under the laws of 4 states, registry activities that use or disclose PHI for clinical services quality improvement efforts undertaken as a health care operation by a health care provider run the risk of breaching the federal line between research and quality assessment or improvement activities, albeit a very gray line.
- Consider whether federal disclosure restrictions, relative to health care operations, would impede registry activities.
- Registry activities that use or disclose PHI for patient safety efforts undertaken as a health care operation by a health care provider may or may not be allowed by state law.

Use/Disclosure Concerning Research

- State laws allow disclosure of public health agency PHI, although the laws offer little practical or procedural information as to the disclosure and too little to determine whether state laws are more restrictive than federal laws.

Question which arose...

- Q: What happens if information goes first to national centers and gets fed back to state public health registries? A: Depends on categorization (e.g. health care operation). Some states specifically state that information cannot cross state lines. Looking at newborn screening laws, needs to be viewed in light of LTFU

Breakout Collaboration Sessions

Three concurrent sessions were held to identify new ways that the NEGC could better collaborate with key stakeholders. For the 2010 annual meeting, breakout sessions were held with the New England Birth Defects Consortium, Families, and Genetics Counselors.

New England Birth Defects Consortium

The group was asked to discuss three questions: 1) What are the goals of the Consortium in the next 10, 5, 1 year(s)? 2) How can the NEGC help the Consortium achieve these goals? and 3) Based on the proposed work

of the NEGC in the coming years, what natural partnerships or opportunities do Consortium members see arising? Where do our interests align? In response, the group discussed:

Goals of the Consortium

- 1 Yr Goals
 - Complete grant application (implement 6 state multivitamin campaign starting Jan.1)
 - Pilot prevalence rates for the 6 states
 - Conducted evidence based review to identify 12-13 commonly collected defects
 - Posting results to website
 - Introduce more people to the consortium (engaged through NEGC and other groups, WIC). Hold initial discussions with environmental health tracking people
- 5 Yr Goals
 - Sustainability – funding through additional sources
 - Group is committed to voluntary support to the consortium
 - Develop protocols for birth defects programs on how they classify data
 - Create a paper defining a protocol for the region
 - Promote use of data on website and help others utilize it

Other Areas to Address

- Natural Partnerships
 - Partner with EHDI programs and newborn screening (some states are currently aligned)
 - Integrating with CSHCN programs
 - Referral care piece... what happens to cases, receipt of appropriate care after born?
- Referral to Care and Services
 - Differences on clinical care end... how to engage clinicians long term... id standardized ways for care as ongoing goal

NEGC Support for the Consortium

- Advertise and promote the work of the Consortium
- Work out a Webex to discuss Michelle Winchester's legal analysis as well as EHDI LTFU issues (in 2011)
- Combine to apply for larger grant opportunities
- Note that Consortium components are part of a national network. New discussions developing around prenatal diagnosis (in process). Once completed, would be helpful to work with clinical partners to review and refine protocols

Families

The group was asked to discuss four questions: 1) What kinds of information would be most useful to include on the NEGC website? 2) What do you see as the major barriers / facilitators to care? Have you noticed any changes in the way care has been provided to your family (e.g. time for appointments, coordination of care, insurance coverage, etc.)? 3) Given the mission and objectives of the NEGC, in what ways can the NEGC improve services for families? and 4) Given the mission and objectives of the NEGC, in what areas do you see a

need for greater consumer/family member involvement? Is there interest in forming a consumer committee? What would its role be? In response, the group focused on how the NEGC could improve the system of care, identified areas for greater consumer / family involvement, and addressed some of the major barriers/facilitators to care.

How can NEGC improve system of care?

- Address standard of care
- Communication with specialists and pediatricians
- Support medical home / medical neighborhood
- Focus on life cycle / continuum of care
- Develop health care systems
- Address policy and health care plans
- Address health care plans and insurance policy
- Provide updates in regular NEGC communications re: health care reform implications

Areas for greater consumer / family involvement

- Leadership, more family involvement
- Provide support for families to be involved
- Review health care bill, distribute to different partners
 - Note continuum of care and different complexities in care.... Importance of communication at different levels throughout the life course; assess how this is affected by the health care bill
- Methods
 - Conference calls, website participation
 - Involvement in evaluation
 - Participate on work groups
- Note the need for monetary compensation

Major barriers / facilitators to care

- Drops in Katy Beckett enrollment
- Educate families of newborns who have died re: importance of screening results
- Communication – importance of consistency and quality among all involved in the medical care team
- Children with special health care needs (CSHCN): less direct services being provided and higher case loads among providers
- Electronic Health Records (EHR): use of technology to speed up the process
- Patients Like Me (social media)
- Teach parents: systems, rights for medical care
- Genetic Alliance – support for parents knowledge
- Medical emergency website

Genetic Counselors

The group was asked to discuss six questions: 1) What are the challenges/barriers in working with families and care providers? 2) “Hot” topics in the field needing more knowledge to shape the services you provide? 3) How can the NEGC help with these issues? 4) What are ways that the NEGC can involve genetic counselors (including trainees)? 5) Would a survey of all NE GCs be helpful? What kinds of questions should be included? and 6) What kinds of information would be helpful to include on the NEGC website? In response, the group discussed:

Hot topics in the field

- Education (to pcps, insurance / 3rd party payers)
- Policy issues (reimbursement, coverage of services)
- Harmonizing carrier screening results to newborn screening and beyond – what happens to info over life course and how communicated
- Community based support services (disease specific peer support groups – some national, less so available regionally)
- Role of genetic counselors in transition
 - Serve as liaison with specialists and pcps

How can NEGC help

- Collect data on outcomes of genetic services and models of care (how do we know what works where...) - document ways of triaging patients
 - Address lack of genetic health counselors in public health depts.
 - Work more closely with other health professionals (pa, nurses)
 - Better liaising with public health schools and public health research programs in the region
 - Address cost effectiveness
- Re: policy arena -> IHPP work around policy can provide support
- Create working groups, offer grant programs

Ways that the NEGC can involve genetic counselors, including trainees

- Include in other existing workgroups, and new workgroups; involve in training programs at Brandeis and other areas

Challenges and barriers in working with families and care providers

- Insurance coverage / reimbursement / access to services
- Ability to directly order tests, id physicians in offices where counseling is provided

Would a survey of genetic counselors be helpful? What topics?

- Participants thought this would be helpful, however there was insufficient time to discuss topics.

Kinds of information helpful to include in NEGC website?

- Use this as an opportunity to find better ways to communicate

Workgroup Summaries

Following are the highlights from each of the workgroup's activities in 2010/2011¹.

Medical Home (Chair: Carl Cooley, MD)

- Overall goal – improve number of kids receiving care in a medical home
- Field testing a care coordination plan used by families and care providers
- Participating in the Quality Improvement Learning Collaborative
- Developing a survey of primary care physicians to document comfort/experiences in caring for children with complex conditions.
- Questions
 - Q: Is objective to develop care plans for each of the disorders? A: No, we want to create a generic template; a tool that can originate in a number of settings and be signed on to by family, provider, specialist. It will be more of a communication tool rather than a full care plan. It should act as a stepping stone towards this end.

Transition (Chair: Susan Waisbren, PhD)

- Piloting an assessment tool for measuring successful transition to a medical home
- Creating fact sheets for youth and adults
- Held a Teen Challenge event during the summer of 2010
- Monitoring advances of transition programs
- Developing a new leadership training model that will be implemented in summer 2011
- Participating in the QILC
- Representing transition activities on LTFU
- Seeking partnerships with the national transition resource center
- Coordinating with the national transition interest group
- Questions
 - Q: Despite resources for youth, many are withdrawn at age 18.... Is there policy work that can be done to support youth caught between? A: yes – currently underway, varies by state. Dr. Cooley will pursue.

Dissemination, Education and Marketing (Chair: Leah Burke, MD)

- Further refine the educational tool for teachers
- Create an easily accessible web resource based on the tool
- Continue reviewing regional and national educational material for possible inclusion on NEGC website
- Explore supports for state 211 systems
- Explore collaborations with LEND programs

Quality Improvement (Chair: John Moeschler, MD)

- Development of a registry for use at 5 sites in the New England regions to improve care processes

¹ Information for this section is drawn from either the chair's direct presentation or additional project materials as relevant to provide a more comprehensive overview to the reader.

- Pursue development of a Patient Safety Organization or similar vehicle to support group learning of best practice
- Analyze and present information on analysis of quality improvement data
- Implement a Quality Improvement Learning Collaborative among partnering institutions in the New England area.

Quality Assurance (Chair: Roger Eaton, MD)

- Focus is on comparing analyzed index data versus known follow up information from Connecticut, Wisconsin, and New York on multiple conditions and their corresponding analytes (markers). The overall purpose of this is to improve the clarity of communications to the medical home, discriminate between false positives and true cases, and to better target the use of scarce specialty care resources. An important aspect is to categorize out-of-range results into indeterminate (most likely false positive, requiring only repeat filter paper samples), possible, and probable disease. The algorithms being developed provides an objective means for NBS follow-up staff to appropriately communicate lab results to the provider.
- Developing an emergency preparedness conference that will orient personnel to the strategies necessary for ensuring a continuous flow of critical services and supports for individuals with special medical needs in the event of a major catastrophe (April 2011)

Long Term Follow Up (Chair: Anne Comeau, PhD)

- Focus is supporting access to continued good care and having positive outcomes.
- They have been working on expanding a successful model in Massachusetts to other states in the New England region. An LTFU system has now been codified in Maine and substantive headway has been made in Rhode Island.
- Targeted best practices in hemoglobinopathy in 2010 – working on data elements and seeking to merge these with national data elements. Provided general outcome information (number of people, hospitalizations) and hosted a national meeting of hemoglobin experts.
- December publication of first census data from Long Term Follow Up – documenting how many children at different ages continue in care of a specialist. It was noted that children with cystic fibrosis and hemo continue in care, but this is not the case with metabolic.

Advisory Council

The Advisory Council met at the end of the conference to review the work of the NEGC to date and discuss potential improvements in the year ahead. Much of the focus was on reviewing the innovative grants programs and how to best support this in the future. Some of the questions which arose centered on trying to understand how the grants impact the NEGC and asking how the NEGC can mature its investment in these grants. The Council also explored the linkage between funding innovative grants and family participation; to this end, interest was expressed in the formation of a new Advocacy / Family Committee. The Council also discussed enhancing partnerships with genetic counselors, possibly by adding their participation to each of the workgroups or actively involving them in piloting a shared care model. In discussing the future potential roles of the Advisory Council, the following areas were identified: general guidance to the NEGC, Innovative Grants, Community Grants, ELSI issues, Advocate / Family Committee, and providing feedback on areas of emphasis (service provision, sustainability, training, coordination, research, and innovation funding).

III. Meeting Evaluation & Feedback

At the end of the meeting, participants were asked to complete a one page evaluation. Out of the 65 participants, 10 completed an evaluation form. Participants were also asked to complete a follow up online survey of their experiences. An additional 15 participants completed the online survey which included the original paper version questions as well a few new items (for a total of 25). The following charts provide a breakdown of their responses by topic and question area.

Goals for the Meeting

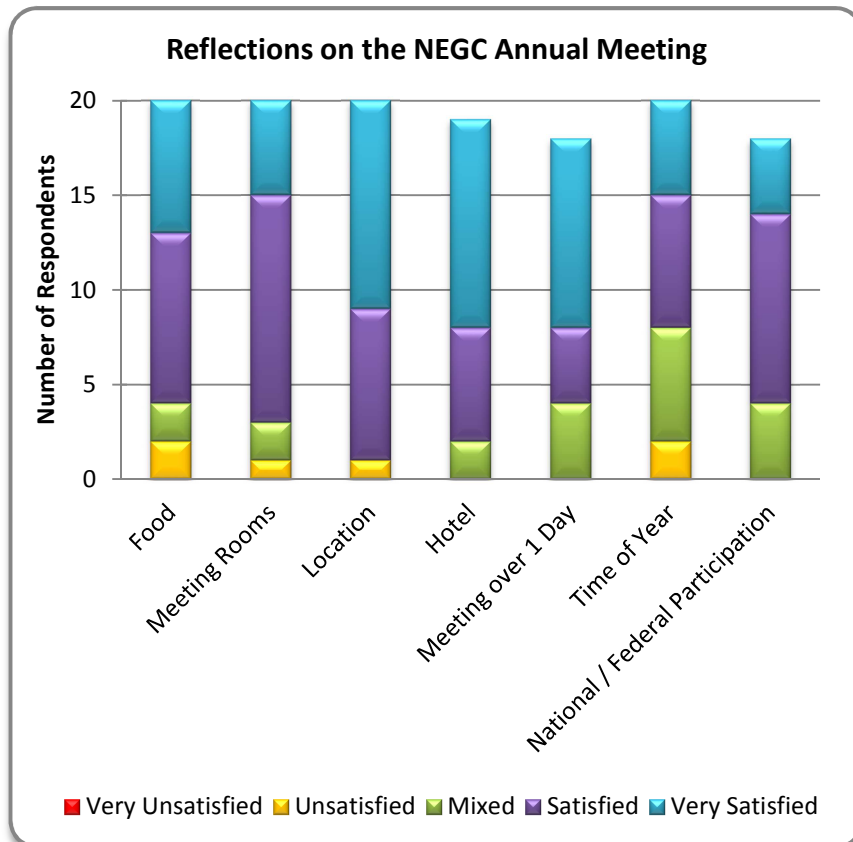
What were participants' goals for the NEGC Annual Meeting?

- Become more familiar with the work of the NEGC (9)
- Learn how they can contribute (3)
- Networking (4)
- Other (3)
 - To present information for the NEGC members and to obtain their feedback on the work of our group
 - Seek collaboration for grants
 - Gather feedback on issues that may be shared throughout the region

When asked whether participants had achieved their goals for the meeting, 10 of 15 responded that they achieved all their goals and five stated that some of their goals were met. No one indicated that their goals were not met.

Feedback on Meeting Structure

Most responding participants were satisfied with the basic elements of the event, including satisfaction with: food, meeting rooms, location, hotel, and national / federal participation. A third of participants had mixed or negative reactions to the time of year that the event was held. Most were satisfied that the event was held in one day.



Feedback on Meeting Process

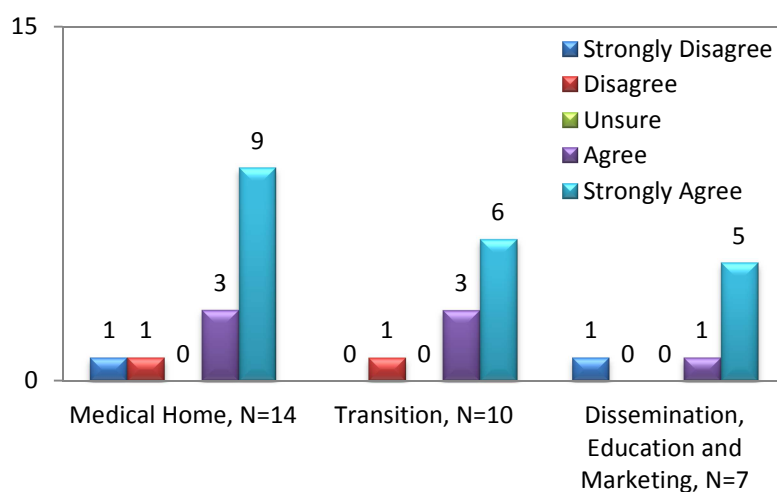
Did participants find it helpful to participate in the workgroup meetings?²

For the Medical Home, Transition³, and Dissemination, Education and Marketing sessions, a majority of respondents felt that their participation was helpful.

Comments:

- Groups need to become educated about ACA (Obamacare) and ACOs (accountable care organizations) [Medical Home / Transition respondent]
- Attending workgroup sessions allowed participation in discussions of activities, findings and plans [Multiple Group respondent]
- The goals of the meeting were not clear and it didn't seem as though we got past how difficult the issues of medical homes, the lack of them, the poor connection between specialty care and PCP's. I would have liked there to be more productivity, rather than revisiting the mission and goals of NEGC for newcomers. There will be newcomers every year. [Medical Home / Transition respondent]

Helpful to Participate in Workgroup Meetings



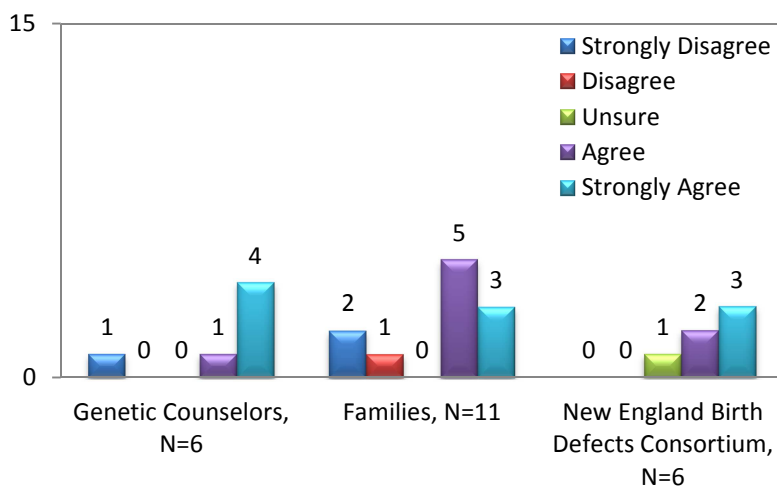
Did participants have an opportunity to share their perspectives?

For the three breakout sessions (Genetic Counselors, Families, NE Birth Defects Consortium), a majority of respondents felt that they were able to participate in the discussion.

Comments:

- There was an [individual] there who tended to monopolize the conversation and tended not to hear other's points. [Family respondent]
- Very important to hear from the

Opportunity to Share Perspective



² includes responses where at least 5 evaluation forms were received for the work group

³ Although participants gave separate responses for the Medical Home and Transition categories, the meeting for these two groups was combined.

families-we learn so much from their experiences-good and bad.[Family respondent]

- Attendance at this meeting provided an opportunity to learn about this activity. [NE Birth Defects respondent]
- This was the most productive session. Hopefully, there will be follow through on the ideas generated [Family respondent]
- This was a wonderful combination of counselors and "counselor friendly" folks. I think some wonderful ideas were expressed and some real potential projects were proposed. I am excited to see where this goes [Genetic counselor respondent].

What was participant reaction to the federal presentations?

Participants were asked whether the presentations by Sarah Copeland, Judith Benkendorf, and Amy Hoffman provided them with a clear understanding of current federal initiatives around improvement of genetic services. Of 25 responding, 4 were unsure, 17 agreed, and 4 strongly agreed.

Comments:

- Compared to the 2009 NEGC session, not much was offered this year.
- This took entirely too long and I was very disappointed not to hear Michelle Winchester's presentation
- Judith - no. Sarah and Amy yes.
- Timing became an issue and Amy's presentation was cut short and it felt a bit rude.
- The presentation by Amy Hoffman was very helpful in understanding this project.
- Technical issues and time management impacted the effectiveness to some degree.

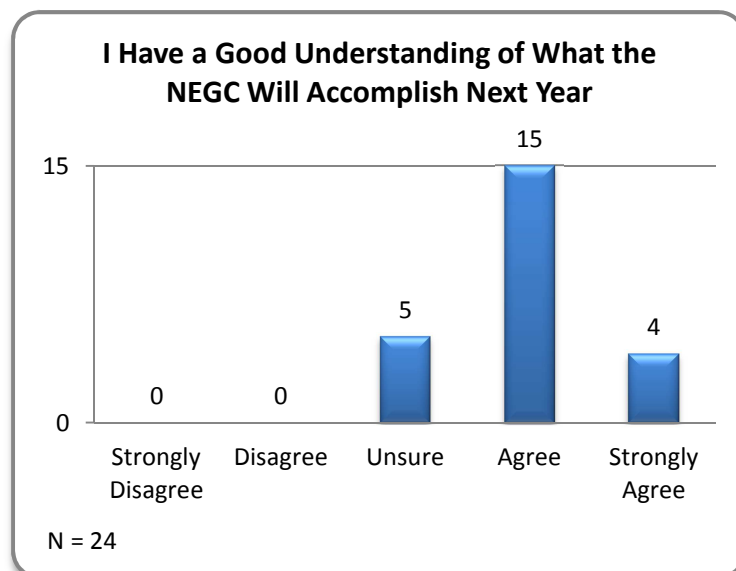
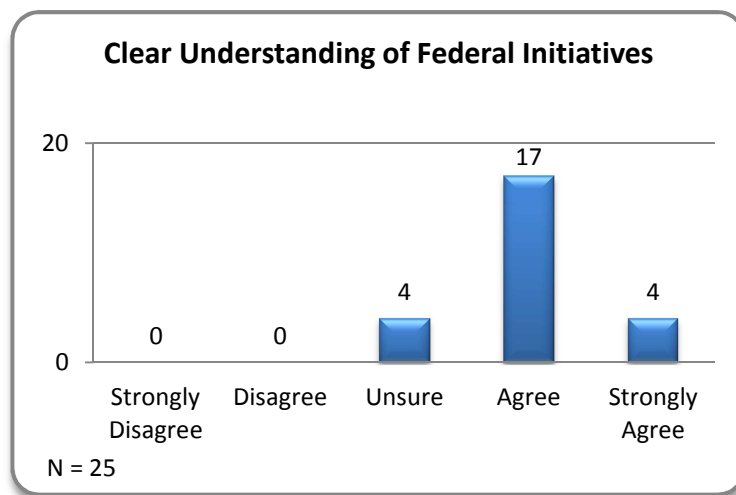
Feedback on the Direction and Progress of the NEGC

I have a good understanding of what the NEGC will accomplish over the next year.

Out of 24 responses, 19 agreed and 5 were unsure..

Comments:

- Learned more about plans for next year at the meeting
- Last year of this grant cycle. Not sure exactly where things stand.



I understand how my work will fit in to NEGC activities over the next year.

Out of 25 comments, 15 agreed, 8 were unsure and 2 disagreed.

Comments

- NONE

The NEGC is headed in the right direction.

Out of 24 responses, 19 agreed and 5 were unsure.

Comments

- Formation of consumer committee is great
- NEGC appears to be working in isolation of health care delivery and payment reform

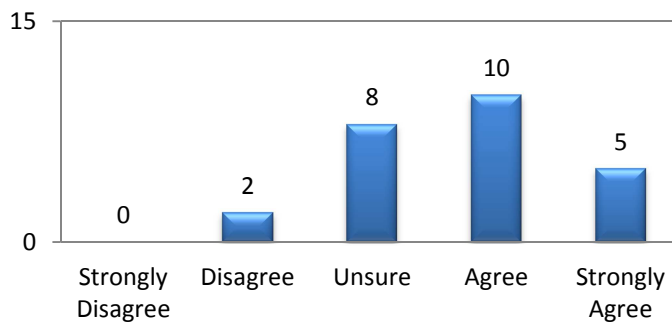
The work of the NEGC has resulted in tangible outcomes that have resulted in improvements in the accessibility of high quality genetic services in the region.

Out of 24 responses, 17 agreed, 6 were unsure, and 1 disagreed.

Comments:

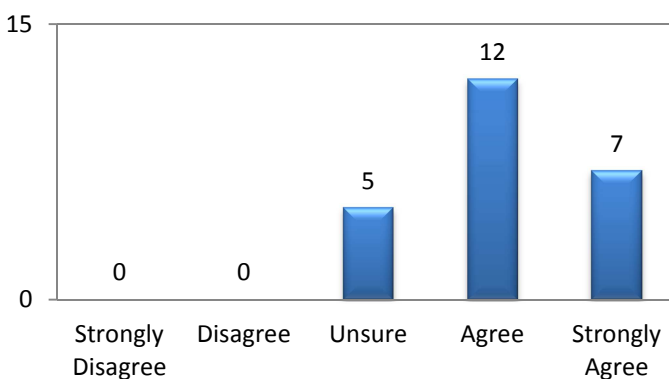
- Learned more about this year's accomplishments at the meeting
- There seems to be some progress being made by some of the workgroups however I am not sure that it is translatable in to improved accessibility of genetic services in the region.
- Some work groups are making progress

I Understand How My Work Will Fit in to NEGC Activities Over the Next Year.



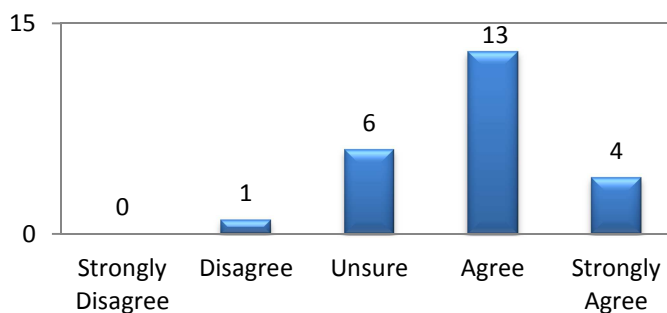
N = 25

The NEGC is Headed in the Right Direction



N = 24

Work of the NEGC Resulted in Tangible Outcomes Resulting in Improvements in Accessibility of High Quality Genetic Services in the Region



N = 24

Other groups which should be involved in the NEGC

- General Groups Needing Outreach
 - Administrators at major New England medical centers (to help boost support from "the top")
 - Family advocate groups in all states, consumers. The NEGC needs to consider that asking families to participate for our benefit has a cost for families. It's not only the travel expenses, but time away from their jobs, need for childcare to work for the NEGC, etc. Families also want to see meaningful outcomes for their participation.
 - School nurses re: transition care, involved in daily life of kids with genetic conditions; should be educated about medical needs/emergency plans, etc.
 - It was good to have genetic counselors present. Maybe the state AAP chapters and primary care providers. Not many will show up, but it's a way to let them know about NEGC and there may be a couple with a special interest. MCHB state implementation grant leaders (CT, ME, NH, maybe MA, maybe others) may have an interest at least in the transition and medical home aspects of the NEGC. Also, LEND program trainees or faculty.
- Targeted Groups Needing Greater Outreach
 - Organizations such as the March of Dimes (2), Save Our Babies, etc. should be featured organizations so that the NEGC can learn about their initiatives and how it affects the Region and how we might take advantage of any opportunities these organizations have.
 - Work with state Medicaid leadership, as well as AAP, AAFP, ACM, CCPCMH on developing health care reform

Other Recommendations Offered by Participants

- Positive feedback
 - I liked the idea for a consumer committee.
 - It was great. thanks.
 - I thought the meeting was very productive.
 - Thanks for the financial support for state public health people!
 - Nice job with all the details.
- Structure of the meeting
 - Time Management
 - Please try to start on time and stay on time
 - The meeting agenda was a little too tight. There were some presentations that were cut short due to lack of time.
 - Content Suggestions
 - Less national updates
 - More time for sessions
 - I felt that a lot of the group reports were repetitive and lacking in content.
 - I think the meeting should move a little away from so many reports. The work group reports could probably be written or presented on the posters rather than using two hours of the meeting. There should be more cutting edge, keynote type presentations (at least one or two). The one planned for this meeting on state health information laws and rules was curtailed due to time overruns for the federal reports. That was disappointing and a little disrespectful of the speaker. I think the sessions for dialogue among various constituencies have value.
 - As a prenatal genetic counselor, I felt that there was only a very small role for me to play in terms of the NEGC focus as I understand it (strongly based in pediatric and adult

arenas). I was struck by the constant reference to genetics across the lifetime, but that there seemed to be a complete lack of any focus on prenatal life (i.e. prenatal education, testing, prevention, etc). This may be an area for future collaboration, and I acknowledge reflects my bias given my day to day work.

- Participation with NERGG
 - Not sure of the value of coming with NERGG..3 full days of meetings is too much at one time.
 - There was a significant gap in time between the NEGC and the beginning of the NERGG Annual meeting. It was difficult to want to stay around a half day before attending another meeting. Perhaps, have a group activity during that down time or move the meetings closer together.
 - I wish that the interaction with NERGG was not separated from the main part of the NEGC meeting so much. If that is the case next year, I would vote for separating the meetings.
 - I vote for moving the meeting to another time of year. Too many meetings fall in Nov/Dec. It would be helpful to have them spaced out more.
- Food
 - If would be nice if the NEGC would offer healthy options for meals, either at the general meeting or work group meetings. You do have participants who are trying to watch their health. Sausage, eggs, bacon, fried potatoes and sugary muffins and pastries for breakfast isn't helpful. You could also request that salads served are not coated in dressing or have sauces on the side for main dishes.
- Other
 - Questions about the workforce survey which was done which represented a very bleak picture and does not adequately reflect the systems which are operating effectively in state newborn screening programs.

IV. Recommendations

In reviewing the day's events, the NEGC experienced substantive growth in participation for its annual meeting (increased from 48 to 65). Overall, the event was viewed positively, and most participants felt that the NEGC was effective in carrying out its work. With that in mind, a number of recommendations are offered to strengthen future annual meetings of the NEGC.

1) Consider changing the timing of the annual meeting. The move toward holding a one day event rather than two appears to have had a positive impact. However, concerns were still raised around the length of time needed to participate in the annual NEGC and NERGG events. Additionally, a third of participants had mixed or negative reactions to the time of year that the event was held.

2) Make the content of the meeting more active. Material that can be reviewed ahead of time (e.g. workgroup updates, general federal updates) can be provided in advance of the meeting and/or on poster boards during the meeting. Participants would like greater interaction with federal partners, keynote presenters, and topics of interest.

3) If there is a separation from the NERGG event, consider whether a 1.5-2 day annual meeting event is needed. Some of the concerns raised focused on the issue of time management of activities as some events of note (e.g. Michelle Winchester's presentation) got cut short. Participants may also like to hear from more 'hot topic' speakers on cutting edge research or new policy developments across the nation. It

may also be helpful to open up some networking time for participants to review poster boards, ask questions of staff / partners (particularly to address questions of what individual roles could be), and network.

4) Consider a wider array of healthier food options, particularly for breakfast.

5) For workgroup and advisory council meetings, consider holding for a minimum of at least 2 hours (so that full discussion can be held and next steps identified for each group). Also, ensure there is no overlap in staff time across meetings (as happened with the Advisory Council and LTFU meeting). It may be helpful to ensure additional meeting space so that workgroups can start on time in case another session is going longer than anticipated. Concerning the advisory council, enable participation via phone in the event that council members cannot participate in person.