

**New England Genetics Collaborative
Annual Meeting, December 2009**

Meeting Summary

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March, 2010

I. Introduction

This report provides a summary of the New England Genetics Collaborative (NEGC) annual meeting held December 2-3, 2009 in Portsmouth, New Hampshire. The annual meeting is considered an opportunity to work with regional membership to inform and conduct an in-depth work plan review. In addition, the meeting serves as a chance to update membership 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.5), and an overview of the multiple challenges and opportunities for the NEGC (pg.10).

Forty-six individuals participated in the meeting, including physicians, state planners, family members of consumers, and two speakers. Project staff highlighted the key accomplishments of the project over the course of the past year (finalization of the medical home pilot, new tools to aid in transition activities, continued refinement of the special educator tool, multiple presentations and publications), and highlighted major activities to be undertaken for next year (expansion of the medical home pilot, implementation of a data registry for quality improvement, continued refinement of marker analysis in lab testing). Breakout sessions on how to effectively engage with and provide information to consumers were held. In addition, open workgroup meetings were held that enabled cross group and new stakeholder participation in the activities of individual workgroups.

Concerning the overall work of the initiative, members identified a range of both national and regional challenges that need to be addressed, including: national funding focused on adults, role of Medicare changes and influence on the genetics systems, various levels of interest and knowledge among providers in the genetics field, and how to practice medical care more explicitly. While challenges were identified, opportunities were offered as well, including: new tools for consumers, the potential to expand core project areas (e.g. medical home pilot), and helpful resources for improving care (e.g. Mountain State Care Plan). Over their next meetings, it is anticipated that the Advisory and Collaborative Council will take these issues on to identify appropriate next steps for the Collaborative.

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 4, 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. Of potential concern, nine of 22 respondents felt that they were unsure as to how their work would integrate with the NEGC during the next year. In terms of recommendations, participants highlighted a range of groups that the NEGC staff could do additional outreach to: family practice MDs, genetic counselors, and parent advocate groups.

II. Meeting Highlights

Over the two days of the NEGC meeting, participants heard an overview of the core mission and accomplishments of the NEGC, participated in one of two discussion groups focusing on consumer engagement, had multiple opportunities to become involved in one of the open workgroup sessions, listened to important updates from our federal partners, and participated in a poster board session highlighting some of the work of the NEGC.

Forty-six people participated, including a mix of physicians, specialty care providers, state coordinators, family members of consumers, and other service providers. In addition to the overview of the project and special discussion sessions, four 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. Major points covered included an overview of the mission, vision, and charge of the NEGC, a summary of NEGC workgroups and staff, a review of the structure of the collaborative as well as a brief discussion on the theoretical basis of the initiative. Dr. Moeschler highlighted some of the activities in the past year, particularly supports provided for the innovative projects (developing parent-provider partnership plans, developing a New England Birth Defects Consortium, and the Personal Transition Health Plan Project). In reviewing access to the NEGC website, it was noted that NEGC staff have observed a steady increase in unique users accessing NEGC information over the past year and that many of these requests were tied to educational information provided on the site. While discussing the goals for the meeting, Dr. Moeschler referenced the importance of "gathering our collaborative members, engaging partners, developing new ideas and ensuring that the work of the NEGC is moving forward and being responsive to the needs of our constituents across New England."

Concurrent Sessions on Community / Consumer Engagement

Two sessions on consumer engagement were held. The first, entitled "How to catch and keep your audience: effective methods for communication and education," was led by Amelia Chappelle of the Genetic Alliance and Beverly Burke of the DEM work group. The conversation centered around the use of the "Trust it or Trash it" tool (available at www.trustortrash.org). Relating the tool to the Genetic Alliance's Resource Repository led to a valuable discussion of how it could be used in developing communication materials, and in evaluating materials developed by others. Members of the Dissemination, Education, and Marketing work group present in this session continued the discussion of how and if to vet materials posted on the NEGC website. The second session, "How can the NEGC better engage the consumer community over the next year?" was led by Wendy Smith of the NEGC Advisory Committee and Judith Benkendorf from the National Coordinating Center. The discussion focused on four core areas: current NEGC participants; groups that are missing from the NEGC; outreach methods to bring new groups in; and questions to address to assure successful outreach.¹

Workgroup Summaries

Following are the highlights from each of the workgroup's activities in 2009².

Medical Home (Chair: Carl Cooley)

- Activities in 2008-2009:
 - Implementing medical home pilot tools, identifying broader challenges to implementing medical home model in the region

¹ Results from this discussion have been incorporated into Section III of this report (Meeting Evaluation and Feedback).

² 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 of the NEGC to the reader (Drs. Waisbren (Transition) and Eaton (Quality Assurance) were unable to attend the event).

- Focus in 2010:
 - Field test care coordination project, further integration of medical home and transition workgroup activities, participation in the NEGC Learning Collaborative

Transition (Chair: Susan Waisbren)

- Activities in 2008-2009:
 - Creation of transition care plans as well as a process for supporting active patient / family participation, finding new ways to involve youth with metabolic disorders, developing a mental health screening tool for lay persons
- Focus in 2010:
 - Develop assessment tool for transition to medical home, create 8 fact sheets on metabolic disorders for youth and adults, hold conference for adults with galactosemia, pilot transition practice at Children's Hospital, continue leadership training for teens, assessment of best practice protocol by metabolic physicians, participation in the NEGC Learning Collaborative

Dissemination, Education and Marketing (Chair: Leah Burke)

- Activities in 2008-2009:
 - Conducting focus groups to review new educator tool, developing a framework for guiding the integration of external information to the NEGC website.
- Focus in 2010:
 - Create web portal based on tool "Children with Genetic/Metabolic Conditions in the Educational Setting", improve utilization of genetic education materials

Quality Improvement (Chair: John Moeschler)

- Activities in 2008-2009:
 - Development of best practice processes and outcomes, tool identifying key information relevant for care, initial registry for a new database, review of work flow at various clinics in the region
- Focus in 2010:
 - Implement new patient registry at 5 clinic sites, create a PSO to host clinic site data, submit white paper on quality improvement in clinical genetics services, establish the metabolic quality improvement learning collaborative, establish quality improvement clinical process and outcomes for patients with metabolic disorders

Quality Assurance (Chair: Roger Eaton)

- Activities in 2008-2009:
 - Analysis of C3 and C5 markers, analysis of MSMS marker z scores for endocrine out-of-range initial screens, ongoing review of laboratory data from participating states, optimization of lab specific cut offs
- Focus in 2010:
 - Expand analysis work to additional MSMS markers, pursue new indices specific to capacities and data collection practices of participating states, convene collaborative conference

Long Term Follow Up (Chair: Anne Comeau)

- Activities in 2008-2009:
 - Developing legal agreements with participating states that will put LTFU into statute, creating a briefing paper for educating legislators and other stakeholders about the importance of LTFU, census data collection and feedback to clinical workgroups, ongoing review and update of clinical data set
- Focus in 2010:

- Expand documentation of legal authority for participation in LTFU to additional states, test feasibility of expanded data collection, refine quality assurance datasets, convene regional policy and HSR conference

National Activities and Update by Judith Benkendorf, Project Manager for the National Coordinating Center (NCC) and Sara Copeland, Genetic Services Branch

Judith Benkendorf provided a range of updates to the group on national initiatives. These included support for: medical home professorships, special projects (e.g. study of workforce needs in response to expansion of newborn screening process), communicating with different groups about genetics, providing access and coverage for medical foods, continued work on telegenetics, support for bioethics, and new ACT sheets for adult care.

Sarah Copeland provided an update on the developing 2012 guidance for the NCC and RCs and facilitated a group discussion around some of the issues raised.

New guidance for NCC and RCs in 2012?

Concerns were raised about the potential for shifting federal priorities mid-course through a five year grant. Once a guidance is established and regions are funded for a particular plan, it's helpful to know that major initiatives undertaken can be followed through on without substantive changes part way through (as many change efforts can take multiple years to establish and taking resources away from them to support new efforts can undermine goal achievement). As an example, this issue came up during the last three years of the project in region one. Staff were wondering about the emphasis placed on services provided via distance strategies (long distance consultations, etc.) in the federal performance measures. While this was not a priority area for region one and not included as a component of our grant application, questions were raised as to why this was added as a performance measure.

What types of concrete measures can we get from the RCs and NCC for proof of utility?

A concern was raised around the use of the existing national performance measures. By focusing on the lowest common denominator approach, we have been left with a mixed set of indicators. Some represent the activities of some regions but not others (e.g. tele-medicine approaches, tracking long term follow up systems). Some measures lack value in terms of setting a high bar that has strong communicative value (e.g. whether a region has a plan in place and updates it regularly). It may be helpful to create domains of change that can be directly linked to what different regions are working on, then provide a list of possible measures that people could use to document whether they are successful in that domain.

What would you like from the NCC?

Participants noted the following areas:

- ❖ Assistance with project dissemination: sharing not only what we are doing with other projects, but regularly providing examples of what other regions are doing that we should be considering.
- ❖ Assistance of PR work and clarity of national and regional roles on what can be done. One of the challenges that we run into is the lack of general understanding among the broader public around genetics and sometimes misinformation among providers in terms of what they should know when providing care (what they think they know vs. what is best practice).
- ❖ Greater discussion around implications of medical home across a broad range of providers (it was noted that while the field has grown somewhat over the last 10 years, there are still many that have not bought

in), onset of disease during childhood, and the importance of transition to adulthood and maintenance of care.

How can we strengthen / document PH departments and Title V links?

Do more to engage schools around public health (creation of workgroups, activities). Also, increase membership to the NCC; encourage greater participation between geneticists and medical home; work with existing programs in various states and seeing if NCC can link to them.

III. Meeting Evaluation & Feedback

At the end of the meeting, participants were asked to complete a one page evaluation. Out of the 46 participants, 18 completed an evaluation form. Participants were also asked to complete a follow up online survey of their experiences. An additional 8 participants completed the online survey which included the original paper version questions as well a few new items. The following charts provide a breakdown of their responses by topic and question area. Relevant information gathered from group discussions during the meeting has been incorporated into this section.

Goals for the Meeting

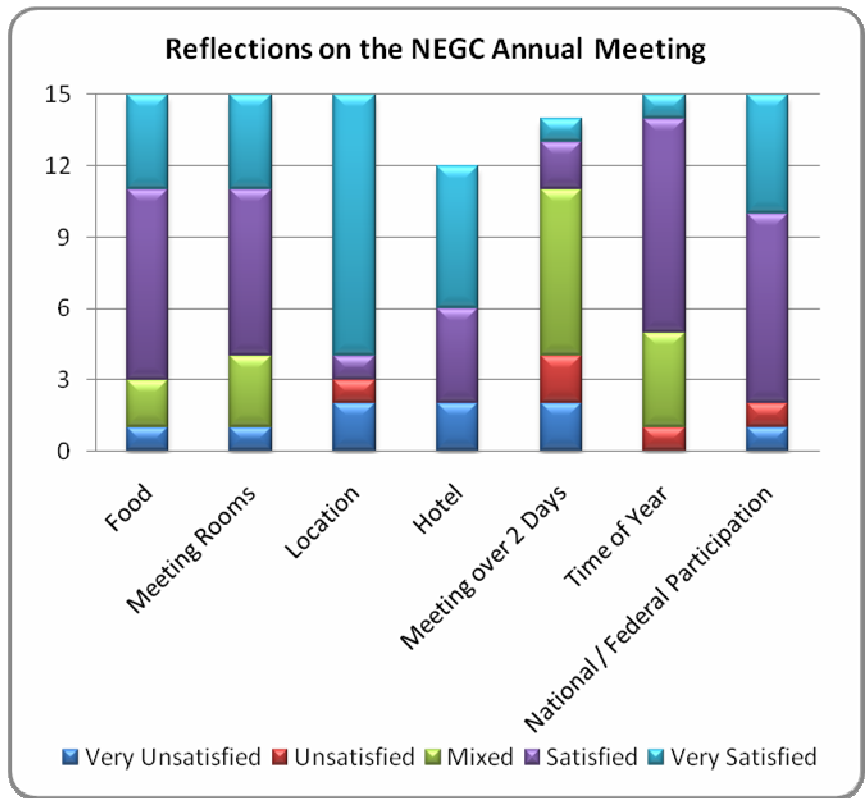
What were participants' goals for the NEGC Annual Meeting?

- ❖ To gain a better understanding of individual work group projects
- ❖ Learn what NEGC is doing and participate in the advisory board meeting, of which I am a member. However, I was not able to attend the advisory board meeting because it was scheduled during the NERGG meeting.
- ❖ Workgroup meetings
- ❖ Integrate genetics and newborn screening into to health care reform, specifically related to ACO, HIT, and PCMH
- ❖ Collaboration opportunities
- ❖ Contribute to the NEGC process nationally and regionally.
- ❖ Get update on natl. activities. NEGC activities. provide input as needed for Advisory Committee decisions
- ❖ Provide an NCC update
- ❖ Learn what is going on in the regional collaborative
- ❖ Take away ideas
- ❖ Assess whether there is anything for which NCC can be of assistance to RC, or take to a national level
- ❖ Lend technical expertise as needed
- ❖ Network/visit with RC members and stakeholders

When asked whether participants had sufficient time to accomplish their goals, 12 of 14 indicated they had sufficient time while 2 stated they did not.

Feedback on Meeting Structure

Most responding participants were satisfied with the basic elements of the two day 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. Two-thirds indicated a mixed or negative reaction to holding the event over two days.



Feedback on Meeting Process

It was helpful to participate in the open workgroup meetings.

Out of 19 responses, 18 agreed and one disagreed.

Which Workgroups Were Attended?:

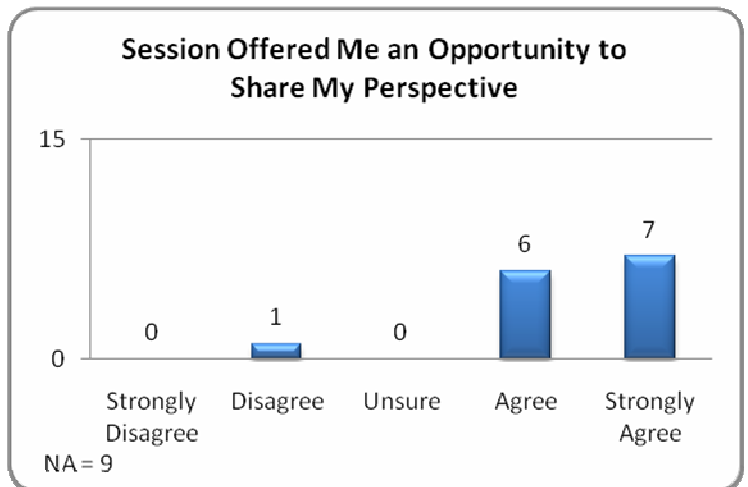
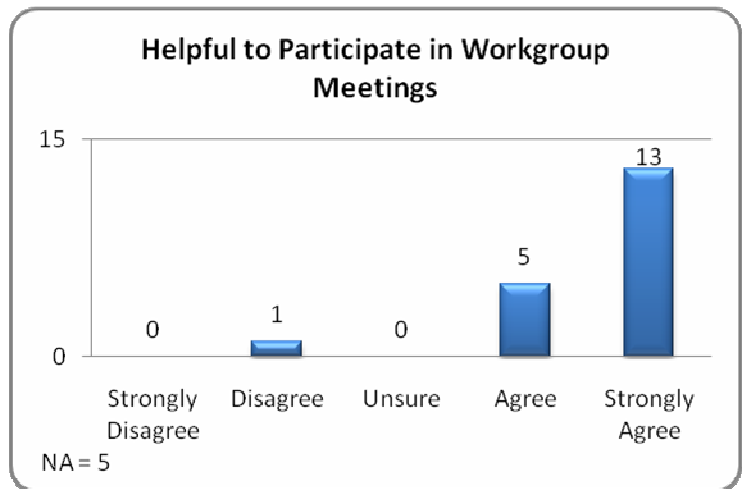
- ❖ Transition & Medical Home (5)
- ❖ DEM (2)
- ❖ QI (1)
- ❖ LTFU (1)

Comments on Participation:

- ❖ The work groups was the most productive part of the meeting
- ❖ Diverse stakeholders sharing their expertise and experience

The session on Consumer Engagement and Communication offered me an opportunity to share my perspective and contribute to the discussion.

Out of 14 responses, 13 agreed and one disagreed.



Comments:

- ❖ I'm not sure whether there is yet a total buy in for consumer engagement. I sometimes feel it is only validated because it is required. Engagement at the most basic level - in practice when a patient is seen in the medical setting is often not practiced because it is too time consuming
- ❖ The communication session was excellent; the speaker Amelia Chapelle was great.

Feedback from the Advisory Committee

Seven people said they participated in the advisory committee meeting.

Did participants have sufficient time to review and discuss meeting topics?

4 out of 5 said yes.

Comments:

- ❖ Yes, materials were sent before-hand.
- ❖ I came as a visitor so I cannot respond to these questions.

How many Times Per Year Should the Advisory Committee Meet?

Once Per Year: Three out of Five. Twice Per Year: Two out of Five

Comments:

- ❖ With conference calls as need arises.
- ❖ At least once; twice if there are issues that warrant the group being together.

Reflections on Participation with NERGG

Eight respondents attended the NERGG meeting.

Should the NEGCC continue holding its annual meeting in tandem with the NERGG annual meeting?

Eight of ten said yes.

Comments For:

- ❖ It is difficult to overlap meetings, because I have to chose which meeting I will attend for a portion of the time. However, it is unlikely I will get approval to travel out of state for 2 meetings at different times.
- ❖ Complements policy making and education
- ❖ If the goals of the 2 groups mesh and this arrangement is of mutual benefit. One benefit I see as an "outsider" is that the genetics clinicians are exposed to RC activities and will hopefully become more engaged.

Comments Against:

- ❖ NEGC needs adequate time devoted to this meeting. The schedule has become too full to tag onto the NERGG meeting and not lose something in the process. 3 days was too much in my opinion.
- ❖ I think it is too hard for people to take off so much time in a row so I'd suggest the main meetings be at different times. However, I think there should be a session at NERGG that focuses on NEGC activities and I think it's fine to coordinate certain meetings, activities if there is overlap and convenience to having them be next to each other. But maybe having the main NEGC annual meeting be at the same time is too much.

Comments Other:

- ❖ Does not matter to me
- ❖ Not sure (2)

What other groups should be involved in the NEGC?

- ❖ General Groups Needing Outreach
 - Other National Groups; state / dept programs, to attract geneticists, and other genetic professionals to participate. CLSI (re: new guidelines for premature and sick newborns)
 - Genetic counselors in New England
 - Parent Advocate Groups
 - Other Genetic Disorders
 - Parent Groups
 - Affected Individuals
 - Targeted Interest areas
 - Childbirth Educators
 - 3rd Party Insurers
 - School Based Health Providers
 - Safety Net Programs (various health providers)
 - Newborn Hearing (also add to long term follow up working group)
 - Family Practice MDs
- ❖ Targeted Groups Needing Greater Outreach
 - LEND program
 - SIMD (Society for Inherited Metabolic Diseases): consider presenting at their national meeting. (transition and care coordination are issues too infrequently discussed).
 - NERGG
 - Developmental Disabilities Council
 - March of Dimes
 - Save our Babies
 - B-3 Program Staff and Parents

What methods should we use to outreach to new groups?

- ❖ Targeted surveys (review existing resources)
- ❖ Develop a broader interface to expand our user base (e.g. NEGC newsletter / mailing list)
- ❖ Survey major groups with our questions
- ❖ Review what other groups have done to outreach (e.g. Alliance website, Region IV, Michigan Bio Trust)
- ❖ Utilization of PSAs

What questions need to be addressed by the NEGC if we are to successfully outreach to parent / consumer groups?

- ❖ What can we offer?
- ❖ How do we engage parents to adopt a regional role?
- ❖ How can we educate parents to help set the stage?
- ❖ What supports do parents need to participate (care, training, transport, economic)
- ❖ What are some of the issues around perceived satisfaction which need to be addressed? What do they understand about “Quality of Care”?
- ❖ What kinds of questions do parents/consumers have?
- ❖ What are the demographics of involved consumers?
- ❖ Who is best to outreach to parents and groups?
- ❖ Who do we contact at each group?

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 18 responses, 15 agreed and 3 were unsure.

Comments:

- None

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

Out of 22 responses, 13 agreed and 9 were unsure.

Comments

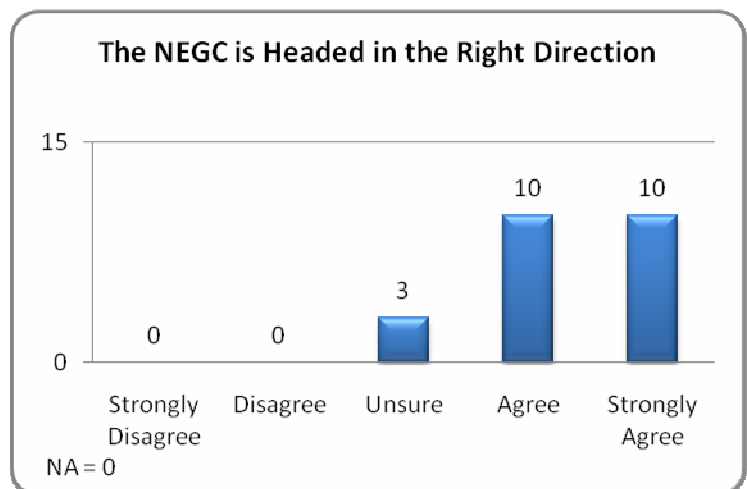
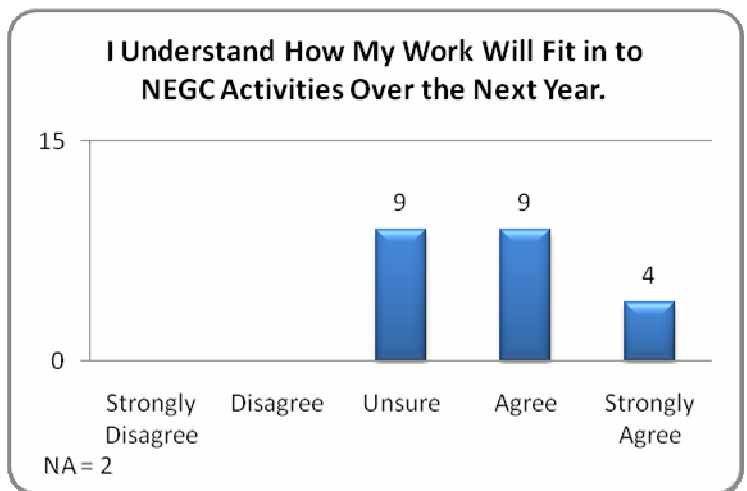
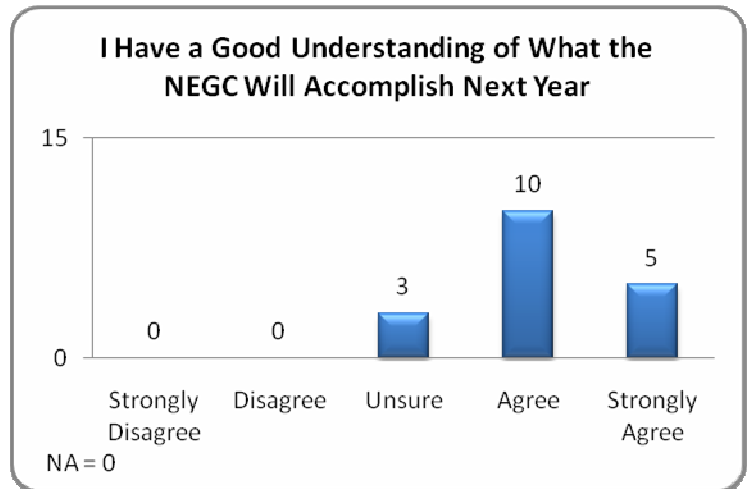
- None

The NEGC is headed in the right direction.

Out of 23 responses, 20 agreed and 3 were unsure.

Comments

- None

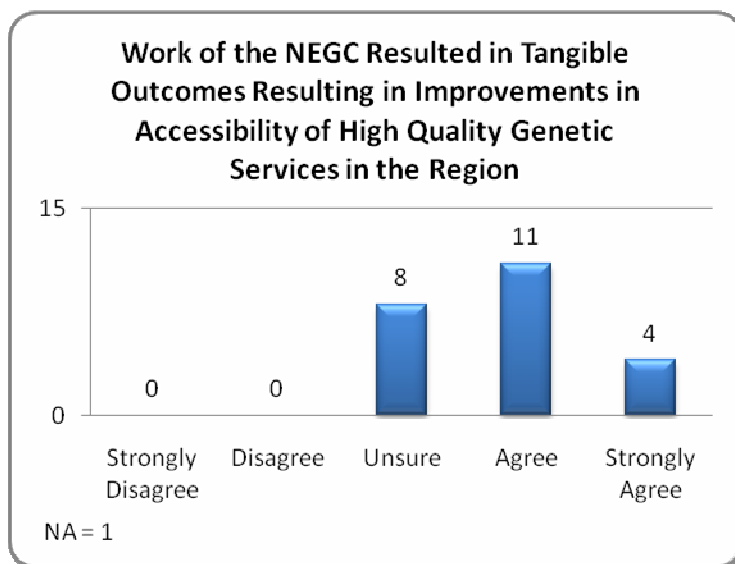


The work of the NEGC has resulted in tangible outcomes that have resulted in improvements in the accessibility of high quality genetic services in the region.

Out of 23 responses, 15 agreed and 8 participants were unsure.

Comments:

- ❖ Very impressed with progress NEGC has made this year. Need to work more to promote progress to stakeholders in New England
- ❖ Progress is evident but not sure it is tangible at this point.



Other Recommendations Offered by Participants

- Please, no overlap w/ NERGG session
- Need a "large" room without a big pole in the center
- Continue the Haiku competition.
- Present an overview of what projects are going on in other regions... opportunity to learn and collaborate.
- Do the NEGC meeting in 1 day. Most of the focus should be on work group meetings, less time spent in the larger meeting.
- The 3 days was a bit much and there was overlap with some meetings which was very unfortunate.

Additional Thoughts Offered by Participants

- I think [that] overall NEGC is progressing well in its goals. It's nice to see what's happening.
- Would have liked to have heard the NEGC overview but couldn't attend the first day. Hearing the committee updates the a.m. of day #2 was helpful.
- Great meeting; nice balance of breakout/small group activities/meetings and large group discussions. Wrap-up sessions might have been shortened, as they were repetitive. I believe it is essential for WGs to leave knowing their next actions. I did not get the sense this occurred with the MH WG. RC should identify overall next actions, as well at the close of the meeting, and make sure those are clear to all.

IV. Looking Ahead: Challenges and Opportunities

In reviewing the discussion held over the two day meeting, a number of challenges and opportunities were identified that merit further consideration.

In terms of the challenges identified, both national and local issues were discussed.

- ❖ National/Regional Challenges

- National funding is typically focused on making changes to the adult system rather than for children. Finding sustained support for development in this area has been particularly challenging.
- It will be some years until electronic health records are widely used as a standard tool. How can we most improve our efforts until that time?
- While recognition of the Medical Home model has increased in a number of regions, there is still a lack of national recognition on the importance and utility of medical practices based on this model. Greater acceptance and practice is needed in this area.
- Inconsistent (or lack of) understanding of the role that changes in Medicare will have and how this will ultimately influence the broader care system.
- Limitations posed by companies which self-insure on individual ability to access care
- There continue to be multiple weaknesses in the broader genetic services network concerning data collection / analysis and building up the evidence base.
- ❖ Regional / Local Challenges
 - Various levels of interest and knowledge among providers (particularly as it relates to the medical home model), as well as parents (participation in LTFU systems). Individuals sometimes state that they know what best practice is, but it frequently seems that their experience and practice falls short.
 - How can we practice medical care more explicitly? How do we address the various legal guidelines around utilization of protected health care information?
 - How can we better gain broad based meaningful input into the creation of the educators chart?
 - Many groups are not represented on the NEGC. There is a great deal of information to bring into the site which needs to be reviewed. We need a process to bring people in and provide them with a meaningful role in the collaborative.
 - We need to have a better understanding of the standards of follow up for different conditions by state with sub-specialty providers.

In looking forward to the work of the NEGC, participants also recognized a number of evolving opportunities.

- ❖ The NEGC is poised to expand several new initiatives that will help to improve services in the region.
 - The medical home pilot project, which seeks to develop a more effective coordination of services between pediatrician, specialist, and family members, will continue to be revised and expanded on.
 - The DEM chart "Children with Metabolic Conditions in the Educational Setting" will be further refined and posted on the NEGC website for dissemination. In addition, the group is looking to expand the tool to focus on a range of specific conditions.
- ❖ Participants of the communications meeting with the Genetic Alliance focused on a review of the Trust or Trash it tool. Members thought it would be a useful template to guide decision making about which resources could be added to the NEGC website.
- ❖ Medical home professorships are being offered to support sharing of medical home expertise across the nation.
- ❖ Input is requested at the national level on developing ACT sheets for the post newborn screening stage.
- ❖ The NEGC should take note of the many advocacy groups that are present in the region and collaborate with them to grow better connections among consumers.
- ❖ The availability of the Mountain State Care Plan provides a useful framework for the possible establishment of a learning collaborative in our own region.
- ❖ The status of LTFU data sharing agreements in Massachusetts and Maine lends itself to further expansion of the LTFU work and may help to provide leverage for improving participation in this effort by other states in the region.

- ❖ New national level consultation resources to assist projects with communication and dissemination of information to stakeholders.
- ❖ New resources and grant opportunities
 - Expanded 340B Drug Pricing Program
 - New grants coming up for early and continuous screening and developing new partnerships

Recognizing that the NEGC is finishing up the third year of a five year initiative, staff noted that this was a particularly critical time for reflection and planning. Since its inception, the NEGC has seen substantial growth in its infrastructure, particularly in regards to enhancing communication, improved utilization of information posted on the website, and other improvements in basic infrastructure and supports so that members could carry out their work. Some of the workgroups, all of which had started out as individual entities with some basic coordination across groups, have begun merging memberships and collaborating on joint projects (medical home and transition workgroup focus on building practices based on a medical home model, collaborations between quality improvement, medical home, and transition on quality improvement activities). In reflecting on next steps, the discussion highlighted several areas of future work and development, including targeted outreach to grow the membership of the collaborative, addressing a range of challenges that continue to influence the future success of the collaborative, and taking advantage of the many new opportunities created by both members and our regional and national partners.