

# **New England Genetics Collaborative**

## **Results of the Stakeholder Survey for Project Year Four**

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### **Summary**

Stakeholder feedback offers a range of critical and helpful insights into the potential next steps for the collaborative as it carries on activities for Project Year Five and plans for a new grant application. To facilitate this feedback, the NEGC conducts an annual survey of its stakeholders to identify concerns, document how the project is doing, and solicit suggestions for improvement. One hundred forty-one email invitations were sent out between October and November 2011 to stakeholders of the New England Genetic Collaborative (NEGC). Of these, one opted out and 63 provided responses (45% response rate).

Since the 2009 report, there was improvement in two important areas. When asked whether they had a clear understanding of the NEGC's mission, 73% agreed (vs. 60% in 2009). Concerning whether the NEGC had made substantive and clear progress in achieving its mission, 72% agreed (vs. 47% in 2009). Feedback on the project's evaluation reports was generally positive with 67% to 70% of respondents indicating that each of the reports helped them understand the progress and challenges of the initiative (vs. 60% to 75% in 2009).

Feedback from the Advisory Council was high this year, with 13 members participating. Most participants (>75%) felt that there was a good spirit of cooperation, that meetings were well run, that the RCC provided excellent support and responded effectively to questions, and that the Advisory Council was achieving its main objectives.

Project recommendations highlight the need for continuing to strengthen communication efforts of the NEGC, identifying new collaboration opportunities for members of the Advisory Committee, making effective use of potential stakeholder contributions, improving consumer/family representation in regional change, pursuing sustainable initiatives, addressing multiple barriers to care for families, and improving access to NEGC resources.

Results are separated into: context of the report (p.2), survey results (p.3), and recommended areas for follow-up (p.9).

## **Context of the Report**

### **About This Report**

This report provides a summary of the results gathered from the 2011 New England Genetics Collaborative (NEGC) Stakeholder Survey. For the purposes of the survey, a stakeholder was defined as anyone who is a current member of the project's Advisory Council, Collaborative Council, one of the six workgroups (Dissemination, Education and Marketing, Quality Assurance, Quality Improvement, Transition, Medical Home, Long Term Follow-up), or other individuals from the region who receive updates on the collaborative's activities. The survey was administered on-line using the Survey Monkey website. Respondents received at least three email reminders to complete the survey and were entered into a raffle drawing for one of two \$25 gift certificates if they completed the survey.

Perspectives represented include: 21 Service Providers, 20 Clinicians, 17 Educators, 17 Public Health, 14 Researchers, 14 Advocates, 13 Family Members of Consumers, 9 State Agencies, and 9 Other. Other includes genetic counselors (3), community organization (2), consultant, policy analyst (2), and NEGC staff. No one indicated that they were participating from a consumer representative. Note that some individuals may represent multiple perspectives.

The survey is part of a larger evaluation effort of the NEGC project conducted by Peter Antal, Ph.D. For a copy of all the project evaluation reports, please download them from [http://www.negenetics.org/AboutUs/Evaluation\\_reports.aspx](http://www.negenetics.org/AboutUs/Evaluation_reports.aspx).

### **Limitations**

The information provided in this report provides a partial indication of stakeholder perceptions after four years of the project's activities. With 45% of known stakeholders responding, many perceptions on project progress remain absent, particularly from individuals who have limited interaction with the project. Given these limitations, the results presented should not be taken as a complete picture of stakeholder perceptions but a guide for follow-up and discussion on areas of concern and perceived strengths that were highlighted by individual members.

### **Data Notes**

Due to limited reporting by workgroup members during the past two years and in an effort to shorten the overall length of the survey, we have dropped workgroup specific questions. For the 2011 survey, we asked only additional questions of members of the Advisory Committee and Collaborative Council. To help protect the anonymity of those who did respond, reporting of the rating data (Strongly Agree – Strongly Disagree Scales) has been suppressed in cases where less than five of the members of a particular group responded to the survey. Comments have been aggregated and are provided in cases where feedback would provide the broader group with potentially useful information. Detailed summaries are available only for those questions which were asked of all stakeholders as well as members of the Advisory Council. For ease of reading, duplicate open comments were collapsed and a number provided indicating how many times a particular thematic issue was raised.

## Survey Results for All Stakeholders

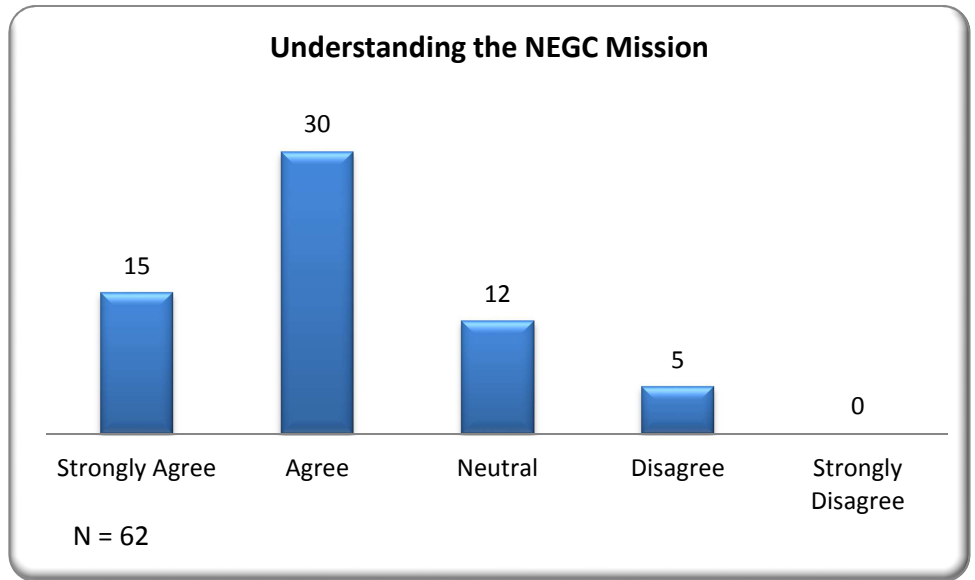
### Understanding Organizational Mission and Impact

*Do stakeholders have a clear understanding of the NEGC's mission and the steps it is taking to achieve that mission?*

Out of 62 responses, 73% agreed, 19% were neutral and 8% disagreed.

#### Comments

- ❖ Have read mission statement, but am curious to learn UMass Med is a partner organization. No one from there has ever reached out to the Mass Family Voices project for family input, to share information, other collaborations, etc.
- ❖ I started receiving information from NEGC, but have never been fully clear as to why I started receiving information
- ❖ The steps to meet the mission are not always clear
- ❖ I need to read more about your group
- ❖ I just started my job as a cancer genetic counselor at Maine Medical Center in May 2010. I was forwarded an email a few months ago from a pediatric geneticist that works in the area about NEGC offering grant money and applied for a grant. I believe that is how I was put on this email list...but I have not received information about the organization itself or its mission.

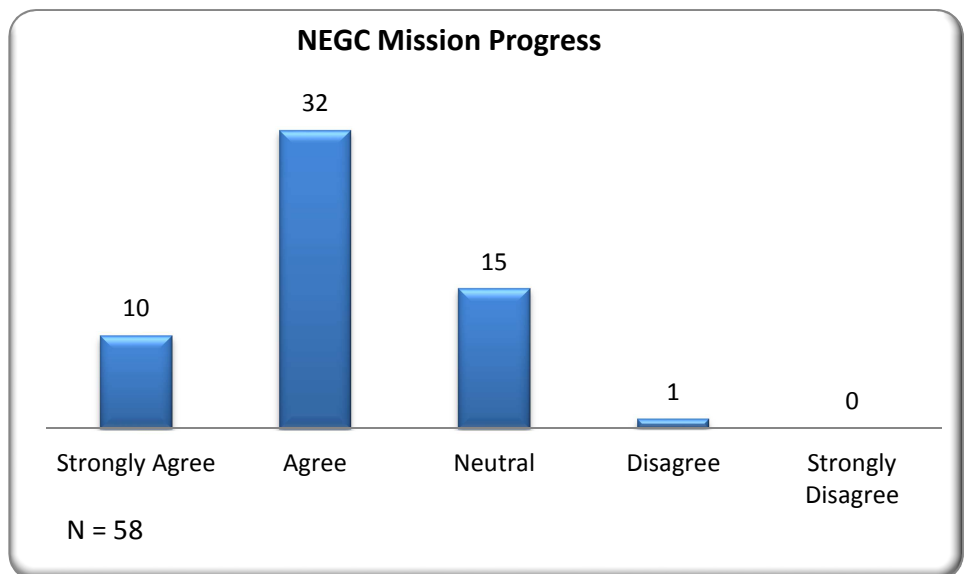


*Do stakeholders agree that the NEGC has made clear and substantive progress on achieving its mission?*

Out of 58 responses, 72% agreed, 26% were neutral and 2% disagreed.

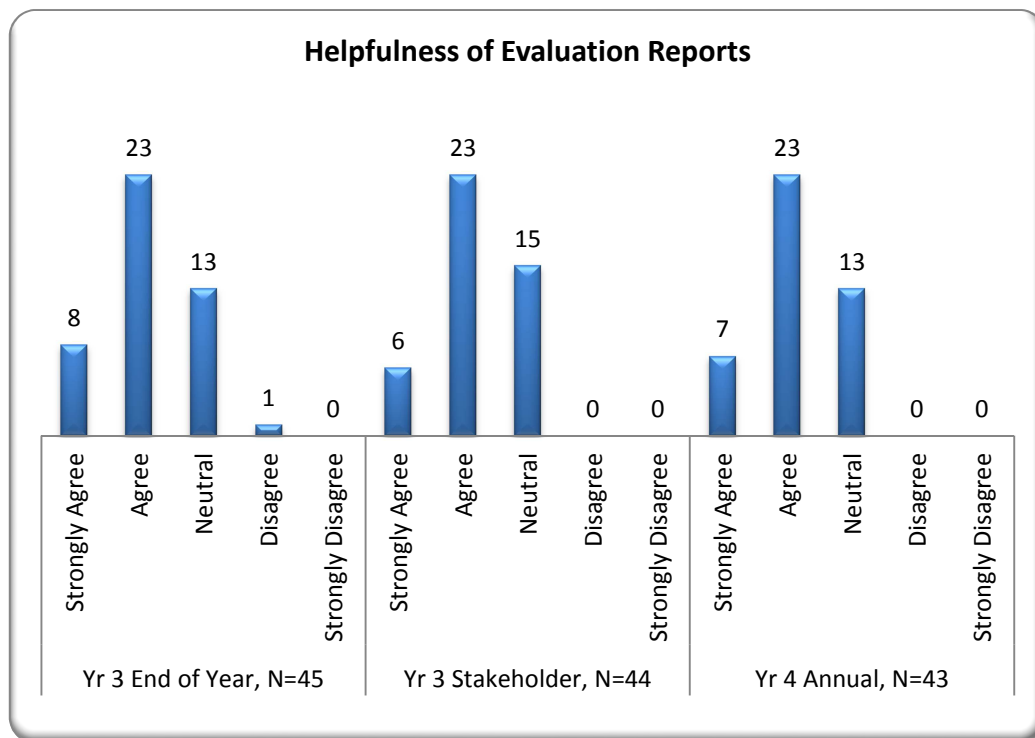
#### Comments

- ❖ Can't comment - not involved in any activities.
- ❖ As I do not know what the mission is, I cannot comment on the progress NEGC has made in achieving the mission.
- ❖ I do think some of the work groups have clear projects and goals
- ❖ From what I read so far in the reports



## Utility of the NEGC Evaluation

*To what extent did the project's evaluation reports help stakeholders understand the progress made to date by the initiative as well as the challenges faced as it moves forward?*



Yr 3 End of Year Evaluation Report (N=45): 69% agreed, 29% were neutral, and 2% disagreed.

Yr 3 Stakeholder Report (N=44): 66% agreed, 34% were neutral, and 0% disagreed

Yr 4 Annual Meeting Evaluation Report (N=43): 70% agreed, 30% were neutral, and 0% disagreed.

### Comments

- ❖ Not familiar with reports (2)
- ❖ Did not read that stakeholder report
- ❖ Plans for sustainability of the projects. It would also be useful for reports to include how findings could be exported to other areas and for other populations.
- ❖ This was the first I have seen the project evaluations..and they were rather lengthy so I did not end up reading past the first few pages. I would suggest a summary of these reports.

## Survey Results for the Advisory Committee

*Is there a spirit of cooperation and collaboration among Advisory Committee.*

Out of 9 responses, 67% agreed, 33% were neutral, and 0% disagreed.

*Comments*

- ❖ I am not aware of any collaboration among advisory council members other than when we have our annual meetings.
- ❖ It is hard when we meet only once a year.
- ❖ Schedule demands do not enable me to attend council meetings

*Are meetings are well run and productive?*

Out of 9 responses, 100% agreed.

*Comments*

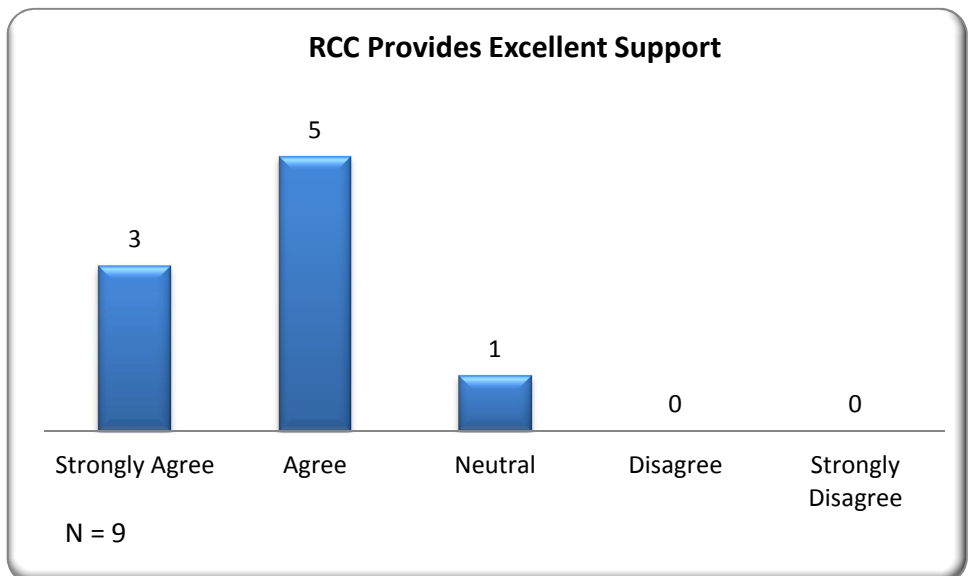
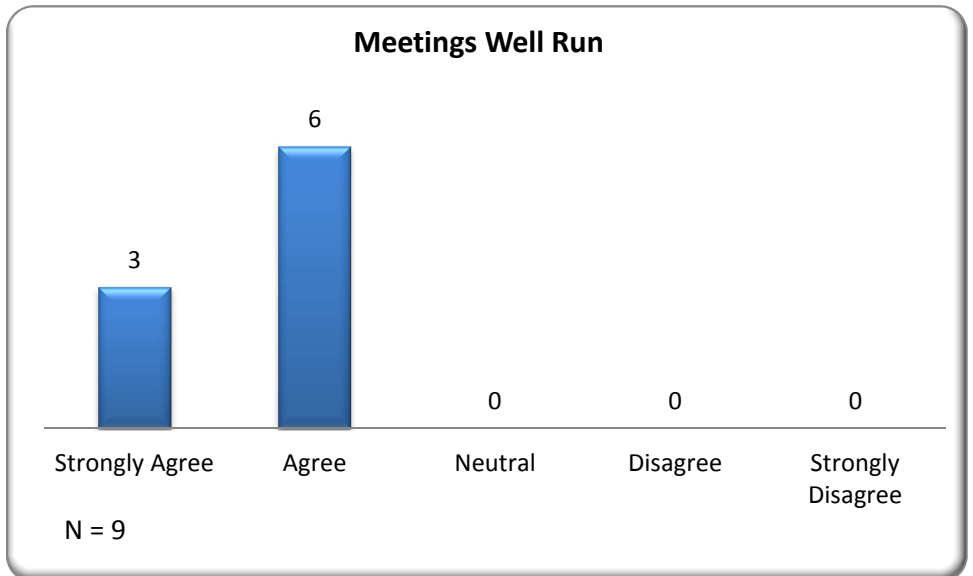
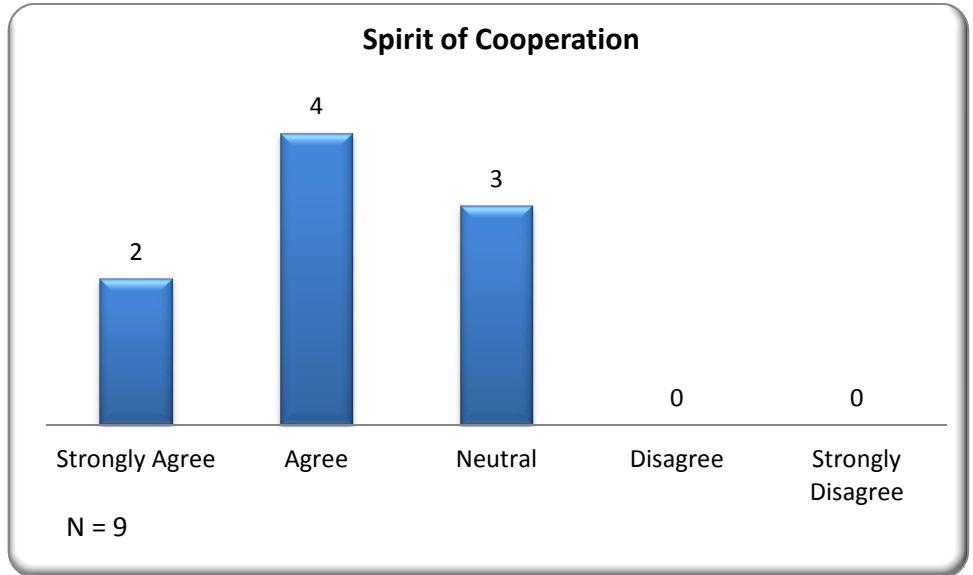
- ❖ No Comments

*Does the Regional Coordinating Center (staffed by John Moeschler, Monica McClain, and Karen Smith) provide excellent support to the Advisory Committee?*

Out of 9 responses, 89% agreed and 11% were neutral. No one disagreed.

*Comments*

- ❖ I agree as far as the minimal requirements are for the advisory council's activities.

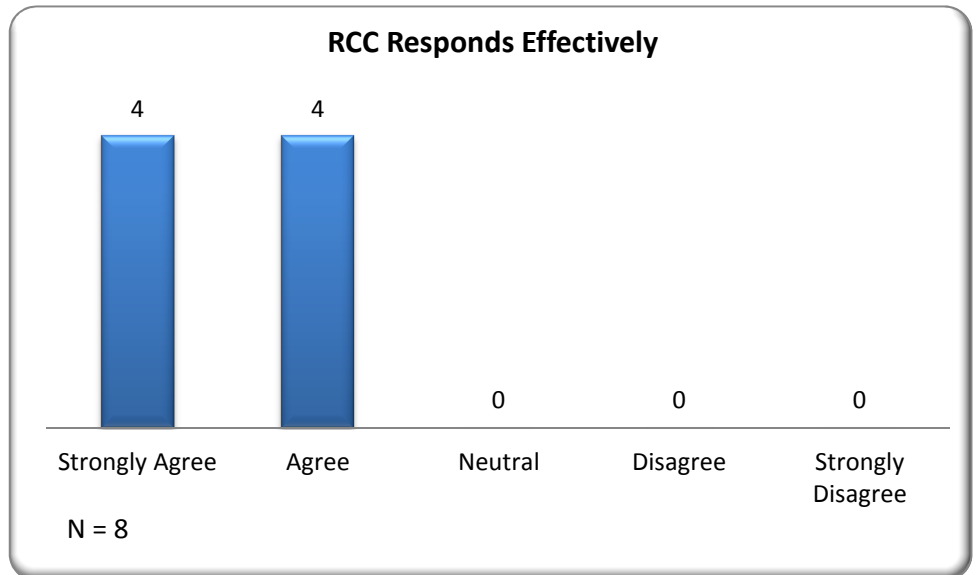


*Does the Regional Coordinating Center respond effectively to my questions and provide useful information?*

Out of 8 responses, 100% agreed.

*Comments*

- ❖ No Comments

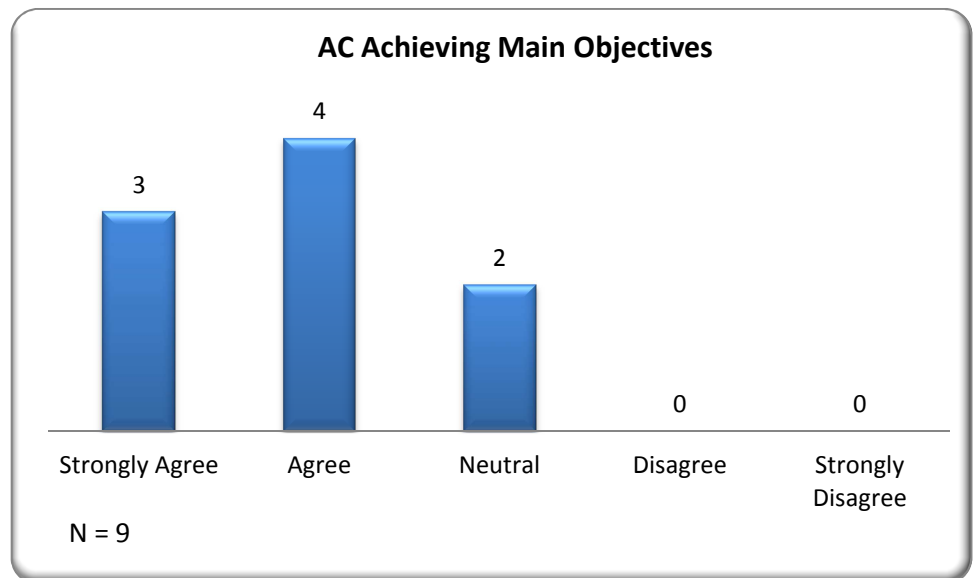


*Overall, does it appear that the Advisory Committee is achieving its main objective of providing guidance and support to the NEGC to address its mission?*

Out of 9 responses, 78% agreed and 22% were neutral. No one disagreed.

*Comments*

- ❖ No Comments



*How often should the Advisory Committee meet?*

Out of 9 respondents, 78% stated semi-annually, 22% quarterly, and 0% yearly.

*What are the strengths of the Advisory Committee?*

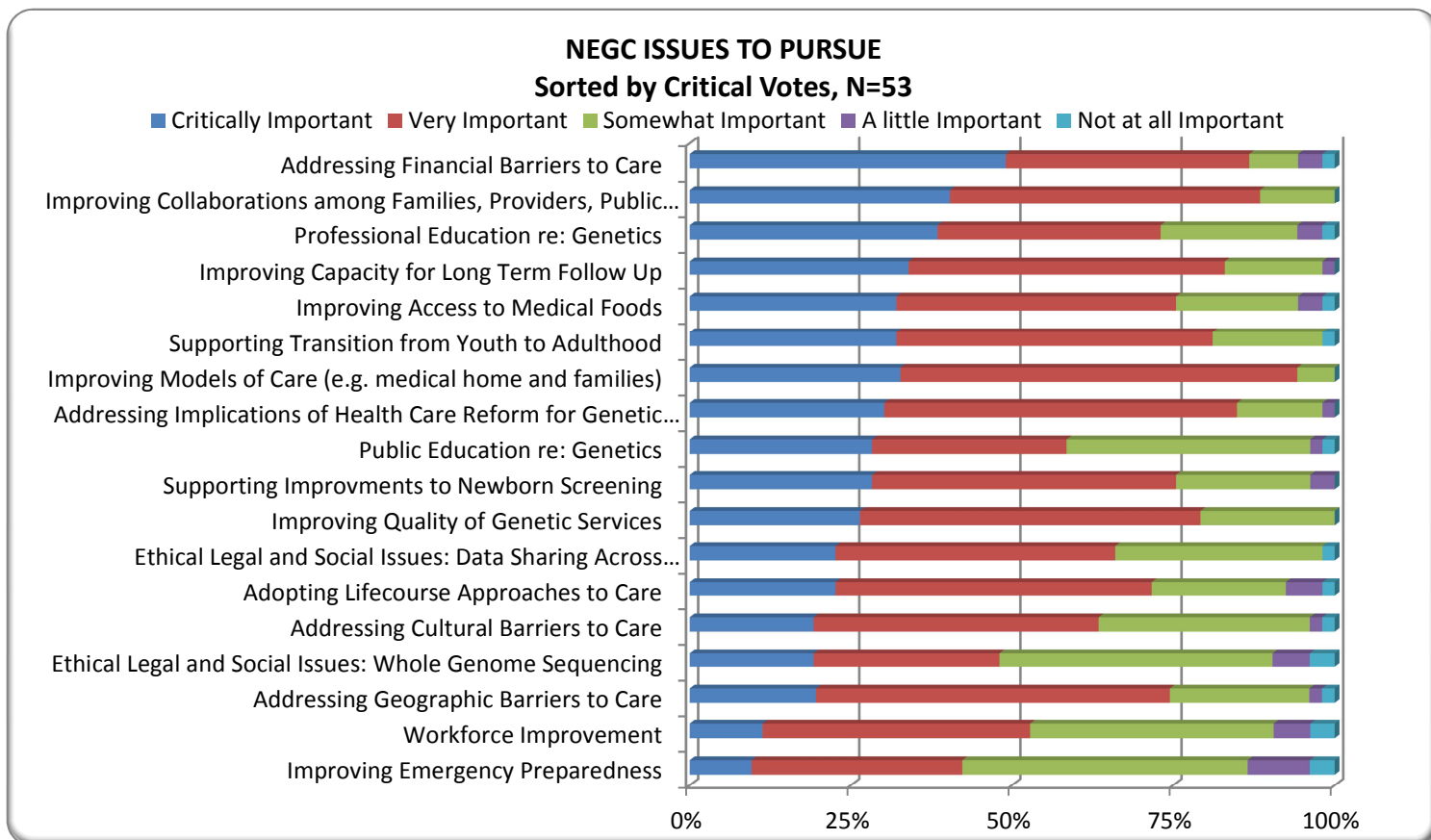
- ❖ Diversity of perspectives (7)
- ❖ Success in achieving goals (2)
- ❖ Other: Respect for all members, whether professional or parent

*What are the main obstacles faced by the Advisory Committee?*

- ❖ Geography (3)
- ❖ Availability to participate (2)
- ❖ Other (4): infrequent interactions, regional or state differences, funding, not clear how much opportunity there is for the council to provide guidance

## Planning for the Future

As a result of the NEGC's work over the past several years, a range of potential issue areas were identified needing further action. To aid in its planning efforts for a new five year grant application, survey participants were asked to rank each of these items on a scale of 1 (Critically Important) to 5 (Not at all Important). The figure below shows the results of these rankings across 18 potential areas.



As shown above, not only are the needs of the New England region diverse, but about 40% or more of respondents indicated that every one of the issues cited above was very or critically important to address. Some of these issues reflect ongoing challenges to the system of care, such as the need for improved collaborations, improving quality of services, addressing cultural and geographic barriers to care. Other areas reflect emerging themes that need greater attention, such as improving access to medical foods, understanding the implications of health care reform on patient access, and ensuring that service providers are linked in to an emergency preparedness plan during disaster events. In addition to the areas cited above, respondents also highlighted the following areas: addressing research, service and intervention gaps for adults with genetic disorders; eliminating disparities and sensitizing providers when accessing care; improving adult screening for hereditary cancer syndromes; and addressing the shortage of genetics healthcare providers.

The NEGC also used the survey as an opportunity for participants to identify their three most important areas and to indicate whether they would be willing to partner with the NEGC on a particular initiative. 63 project topics were identified where individuals were willing to support the NEGC's work. Of these, 39 included individuals who self-classified as proficient or leaders in a specified area.

## Other Comments Provided by Stakeholders

### *Reflections from the Collaborative Council*

Only three of 3 of 7 Collaborative Council members responded to the survey. The following comments reflect feedback from these members.

- ❖ Top 3 Strengths of the Collaborative Council
  - Diversity/Overlap of interests (4)
  - Engaged membership (2)
  - The responsiveness of Karen and Monica
  - Leadership
  - Evaluation
  - RCC is quite awesome
- ❖ Top 3 Obstacles faced by the Collaborative Council
  - Limited time (4)
  - Funding (2)
  - Lack of consumer member
- ❖ What can the NEGC do to support the work of the Council
  - Continue what they are doing
  - Continue the excellent support by Karen, Monica, and Peter
  - Provide draft reports
  - Break the space-time continuum so that I can get more work done
  - Provide reminders
  - Find ways of facilitating more face-to-face work sessions

### *Additional Perspectives*

A number of comments were provided by individuals that are of value for all participants to review. The following comments are drawn from across survey questions.

- ❖ Recommendations
  - Collaborative efforts by some partners in public health are limited due to workload and other institutional restrictions, such as travel. This doesn't mean the work isn't important. Efforts to engage public health should continue. Thanks
  - I would like to see consistent participation in the NEGC by consumers. It's an important aspect that seems to be under-represented.
  - Families of children with special health needs (genetic and otherwise) are still struggling with the same issues: 1) Access to insurance; 2) Access to family-friendly, coordinated, culturally competent, care; 3) Need for competent respite services; 4) Access to transition services (and access to competent adult services for those with ongoing health needs); 5) Access to treatment and follow-up after screening and diagnosis; and 6) Loss of financial security, loss of income. For families, there are too many groups "out there" working on these issues and not enough solutions. What we really want is to be able to help our children lead as "normal" a life as possible and not spend all of our time and energy navigating the health care system which, for us, includes insurance, home care, PCP, Specialists, school inclusion, transition preparation, respite and variable other issues depending on the individual. While we recognize the value of data collection and analysis, it is useless unless it brings about positive change. We can continue to improve our knowledge of genetic conditions but if we, as a society, are not

willing/able to put systems in place which are accessible, competent and sensitive to the needs of families, it is knowledge that will benefit few.

- ...I have found that there are a number of tools available to facilitate health care transition. This information should continue to be disseminated through face-to-face meetings and professional conferences to get the word out about the great work that has been done so far. Many disciplines other than clinicians can assist youth with health care transition, such as community nurses, health teachers, social workers, psychotherapists, physical and occupational therapist etc. These professionals should have tools promoted to them as well, as they have so much contact with youth where they live, work and go to school. Goals should be set and outcomes should be defined and evaluated as the tools are put into place.
- Guess when reviewing this survey, I am unsure who IS on the advisory council vs. collaborative partners. More/increased awareness of the players might be helpful; sharing participant lists.
- It is not clear what the role of this organization is with respect to other professional genetics organizations

❖ Positive Reflections

- First, I am elated that NEGC exist in the region, and that there are resources I might need to investigate more to strengthen the area that I am working in. I am still relatively new and know I have much to learn, but I am grateful for the opportunities that exist in this region of the USA.
- Thank you for all you do, Peter.
- I enjoy working on and being a part of the education committee. Also presently being a part of and looking forward upcoming meetings for the newly formed Advocacy Group
- Thank you for conducting this survey. It is very important.
- I am going to look into the work of your group more, it is very interesting to me. Our young adults and myself have a genetic condition, Fragile X. Thank you for all the work you and your committee does!

## Recommended Areas for Follow-Up

The data collected in this year's survey represented a slight drop in the response rate (58% to 45%) while demonstrating an overall increase in the number of respondents (42 to 63). Although not fully representative of all identified stakeholders (this was a non-random survey, all eligible stakeholders were contacted), the 45% participation rate continues to provide a range of viewpoints and helpful perspectives to take note of. In reviewing the available data, there are seven recommended areas for further action by NEGC staff.

1) Continue to build on outreach and communication efforts with NEGC stakeholders. Although there has been an increase in the percent of individuals reporting that they understand the NEGC's mission or that they find evaluation reports helpful to their understanding of the work of the NEGC, over one in four respondents did not agree with these statements. To help improve public understanding of the NEGC's mission, it may be helpful to include the NEGC's mission and vision statements in the side bar of each NEGC Enewsletter, at the start of direct staff and contracted agency presentations (including workgroup meetings), and as a footer for general email correspondence. Concerning the evaluation reports, it will be helpful to continue highlighting new releases in the ENewsletter as well as on the NEGC website and to produce a short one page pdf summarizing each report for easier public consumption.

2) Continue to review/monitor the level of Advisory Committee integration into the NEGC. Of note, all 9 responding members indicated an interest in meeting more than once a year. However, participants of the 2011 Advisory Committee meeting felt that the level of involvement (once a year for formal gatherings, special meetings as needed) was just right. In preparing for a potential new grant cycle, it may be helpful to consider an expansion of meaningful opportunities for members interested in taking a more active role in the

NEGC's mission (e.g. offering opportunities to participate directly in workgroups, identify and develop new partnerships with regional and national organizations, help identify sustainable resources to ensure continued project supports).

3) Take full advantage of stakeholder offers to collaborate with the NEGC. Given that the NEGC has limited staff capacity to take on all the needs of the region, it would be quite helpful to review and identify potential matches among the 63 potential project areas that participants would like to work on, particularly those areas that include an individual with demonstrated expertise in a particular field area. For these areas, it may be helpful to identify whether working groups could be formed with a minimal level of support by the NEGC. A recent example of this is the formation of the new medical foods workgroup under the NEGC Advocacy Workgroup. Another area of focus should be on identifying new ways to partner with and support better integration with public health departments from each state. Recent work around supporting screening changes of CCHD is one great example. However, there are likely additional areas which could be pursued.

4) Review the potential role of adding a consumer or family representative to the Collaborative Council. Review/Support additional opportunities for incorporating consumer/family participation in the work of NEGC's stakeholders.

5) Support development of sustainable initiatives - pursuit of activities that are specifically geared towards making long term changes to how certain activities are funded and sustained (e.g. supporting education / outreach to insurance groups that will lead to reimbursements via use of appropriate codings for medically necessary treatments / resources, establishing partnerships with regional /national foundations that have long term interests in supporting core projects of the NEGC).

6) For the purposes of a potential five year grant cycle, define or refine meaningful change in some of the challenge areas for families of children with special health care needs and identify a process for creating that change - either directly through the work of the NEGC or through the NEGC's partner organizations. Potential areas to pursue based on one participant's feedback: 1) Access to insurance; 2) Access to family-friendly, coordinated, culturally competent, care; 3) Need for competent respite services; 4) Access to transition services (and access to competent adult services for those with ongoing health needs); 5) Access to treatment and follow-up after screening and diagnosis; 6) Loss of financial security, loss of income.

7) Continue to seek out opportunities for expanding the use of tools created or supported by the NEGC. Conduct an annual review of what is being used/accessed and determine whether new outlets exist that may be tapped to ensure broader dissemination of quality work.