

DRAFT!
New England Genetics Collaborative
Results of the Stakeholder Survey for Project Year Two

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Summary

Between May and June 2009, 68 email invitations were sent out to stakeholders of the New England Genetics Collaborative (NEGC). Of these, 20 (29%) provided responses. Stakeholder feedback offers a series of helpful insights into the potential next steps for the collaborative as it carries on activities for project year three. Respondents suggested new spotlight projects as well as resources to be mapped out on the NEGC website, documented multiple strengths of the collaborative's membership (particularly in regards to the collaborative spirit, commitment and leadership), and identified areas where continued support from the NEGC is needed. Feedback on the project's evaluation reports were generally positive with 9-12 out of 16 indicating that each of the reports helped readers understand the progress and challenges of the initiative.

In several areas of the survey agreement ratings were mixed. On the topic of appropriate NEGC involvement with service providers/decision makers and consumers, about a third of respondents agreed with the statement while one in four disagreed and the rest were neutral. When asked whether they had a clear understanding of the NEGC's mission, 12 of 20 respondents agreed. Concerning whether the NEGC had made substantive and clear progress in achieving its mission, nine agreed, six were neutral and four disagreed.

When asked about the strengths of the collaborative, several common themes emerged across all survey respondents, highlighting: the collaborative spirit, commitment to the mission, leadership of key individuals, administrative support by Karen and Amy, experience of members, communication and open discussion, varying viewpoints and presentation of ideas, clear objectives, common mission, and other.

Concerning some of the obstacles faced, the most frequently cited challenge was time needed for greater involvement in the project, followed by concerns about interactions among members, barriers to utilization of health information technology, lack of fiscal resources, length of time between meetings, geographical limitations, and other.

Respondents were also asked about what the NEGC could do to provide better support. In response, most members focused on the continued need for administrative support (managing due dates, grants, papers, IRB applications), technical support for handling new technology, improved communication, finding new opportunities for members to collaborate on, leadership, and other.

Results are separated into context of the report (p.2), survey results (p.3), and recommended areas for follow-up (p.10). For ease of reading, duplicate open comment responses were collapsed and a number provided indicating how many times a particular thematic issue was raised.

Context of the Report

About This Report

This report provides a summary of the results gathered from the 2009 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 who have had a direct role in the collaborative's activities. The survey was administered on-line using the Survey Monkey website. Respondents received at least four email reminders to complete the survey. 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 www.negenetics.org.

Of 68 invitations sent, 20 responded to the survey. Perspectives represented include: 2 advocates, 6 clinicians, 4 consumer, 9 public health agencies, 3 researchers, 5 service providers, 8 state agencies, and 3 other (genetics nonprofit organization, medical home, and genetic laboratory survey provider). Note that some individuals may represent multiple perspectives.

Limitations

The information provided in this report provides a partial indication of stakeholder perceptions after two years of the project's activities. With only 29% of known stakeholders responding, many perceptions on project progress are missing; particularly from the project's advisory council and the individual project workgroups. 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.

Based on a review of the data, many of the neutral responses are likely tied to individuals not being sure about the status of a particular question; several individuals did not feel fully informed about project activities and so could not provide an informed opinion. This was reflected in individual workgroup comments, feedback by advisory council members, and responses to survey questions posed to all stakeholders. As a general guideline (with some possible exceptions), the relatively moderate occurrence of neutral responses reflect the continued challenges encountered in keeping multiple stakeholders appropriately informed via lines of communication that best meet their time and technological needs.

Data Notes

To help protect the anonymity of respondents, 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. Individual comments across groups are provided in cases where feedback would provide the broader group with potentially useful information. As a result, detailed summaries are available only for those questions which were asked of all stakeholders.

Survey Results

Suggested Resource Maps

NEGC staff have recently posted a resource map of genetic clinics in the New England area (http://www.negenetics.org/directory_test.html). What other resource maps might be useful to include on the NEGC website?

- ❖ Available financial resources to assist patients who have access to those clinics (such as fees/ transportation)
- ❖ Key resources in each state that could assist families - Perhaps the Family to Family Health Information Centers.
- ❖ Location of support groups or meeting sites for support groups with contact information (3)
- ❖ Metabolic clinics
- ❖ Practicing Genetic Counselors if they are not associated with a Clinic, if not already included. Also might want to consider specialists who are experts in serving patients with genetic diseases but who are not genetics docs, but this might be a huge undertaking, for example neuropsych who work with Huntington's Disease, hereditary cancer experts who are non-genetics, etc.

Other Comments

- ❖ Blog; easy upload of documents by WG leaders.
- ❖ Tools/templates for Medical Home development and co-management of care
- ❖ Honestly, I don't have time to look at Resource Maps.
- ❖ Not sure.

Spotlight Projects

The NEGC staff have posted a few examples of "spotlight" projects (see http://www.negenetics.org/state_nh.html for an example). Are there other examples of projects which you would like to see highlighted on the NEGC website? Please describe.

- ❖ Collaborations between primary care and genetics clinics
- ❖ Transition Work Group and the evaluation tools for non-psychologists.
- ❖ Projects from other regions

Other Comments

- ❖ I would like to see regular active recruitment for spotlight projects representing all states in the region.

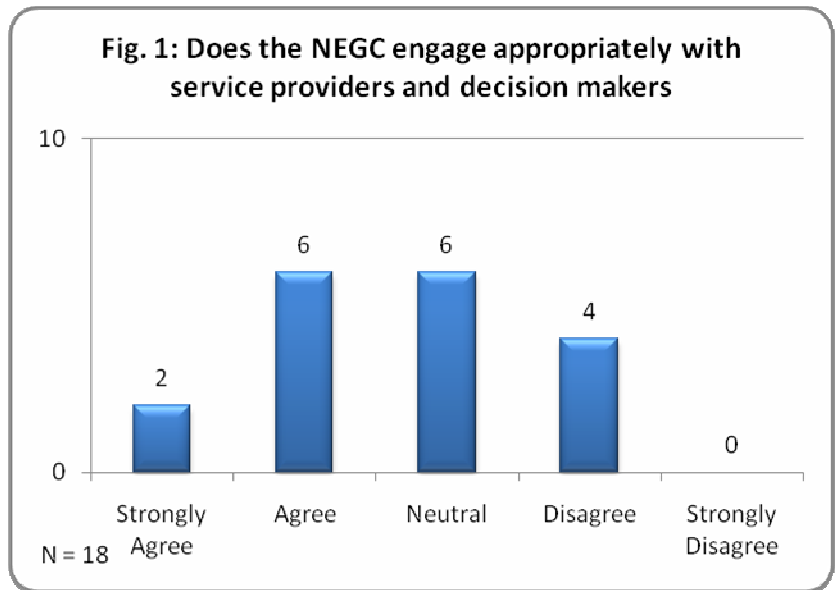
NEGC Involvement with Service Providers and Decision Makers

Does the NEGC engage appropriately with service providers and decision makers in the field of genetic services and supports?

Eight members agreed, six were neutral, and four disagreed.

Comments

- ❖ I don't know (2)
- ❖ Many, if not most, are not aware.
- ❖ Not sure on decision makers
- ❖ The players engaged/involved in the decision making of the regional structure and activities is too narrow with little opportunity for input. Greater opportunities for decision-making in setting regional priorities and within the NEGC itself is needed.
- ❖ Being on the advisory board I only see a small snapshot of what is happening at NEGC so I can't comment specifically on this but my general impression is that there should be more outreach/inclusion of a larger variety of service providers, etc.



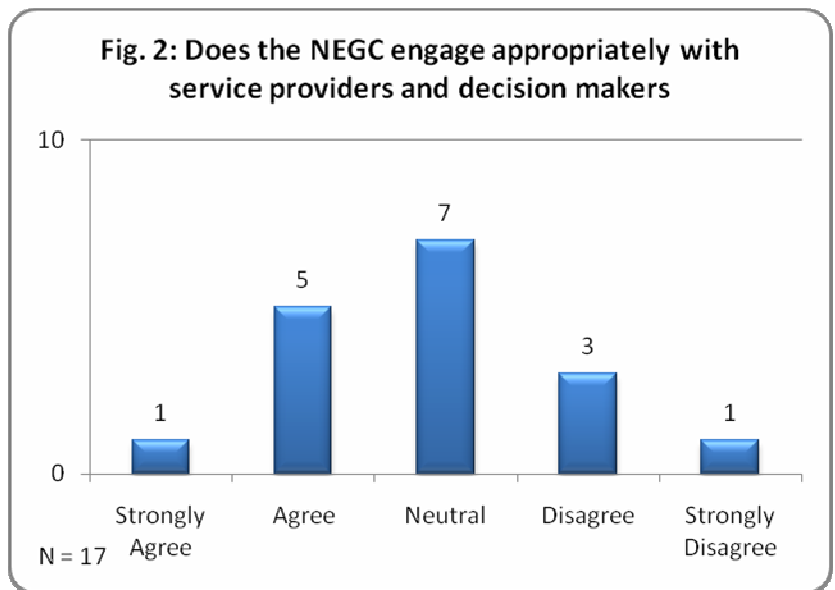
NEGC Involvement with Consumers of Genetic Services and Supports

Does the NEGC engage appropriately with consumers of genetic services and supports?

Six members agreed, seven were neutral, and 4 disagreed.

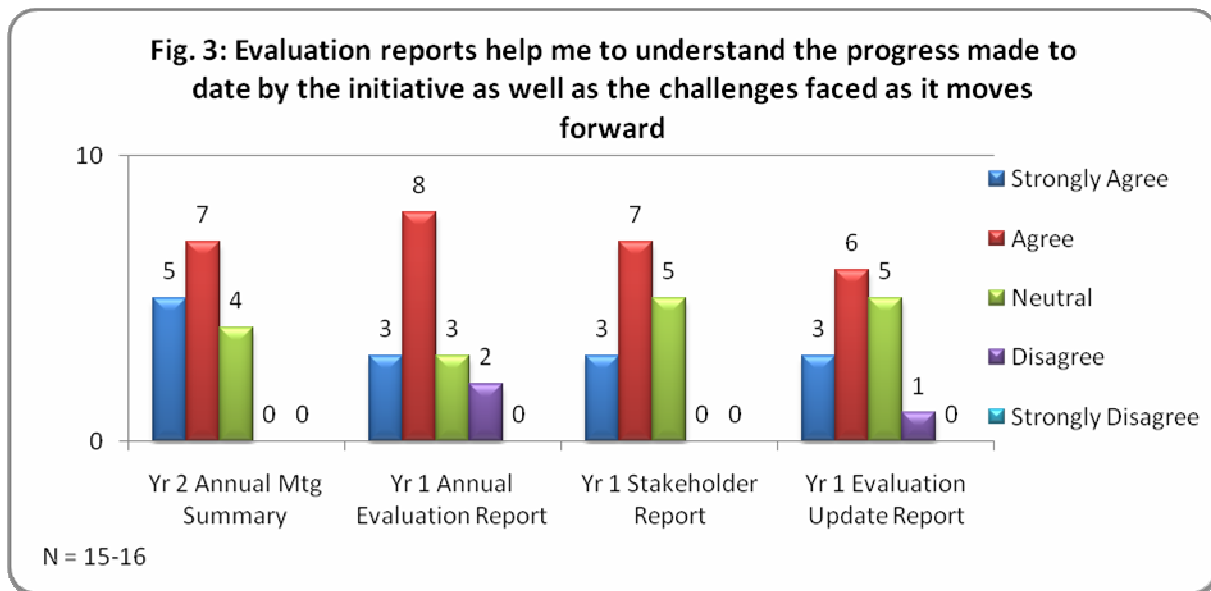
Comments

- ❖ I don't know (2)
- ❖ Many, if not most, are not aware.
- ❖ There has been very little active participation between meetings.
- ❖ This is always a difficult thing to do. I think that there is always room for improvement.
- ❖ Consumers that provide input to NEGC activities should represent the demographics of NE, to include socioeconomic groups, ethnic groups, urban and rural groups, etc. You also need to provide funding in order for consumers to participate in NEGC activities for consumers



NEGC Project Evaluation Reports

The NEGC project's evaluation reports help me to understand the progress made to date by the initiative as well as the challenges faced as it moves forward.



Yr 1 Evaluation Update Report: nine agreed, five were neutral, and one disagreed.

Yr 1 Stakeholder Report: 10 agreed, five were neutral, and none disagreed

Yr 1 Annual Evaluation Report: 11 agreed, three were neutral, and two disagreed

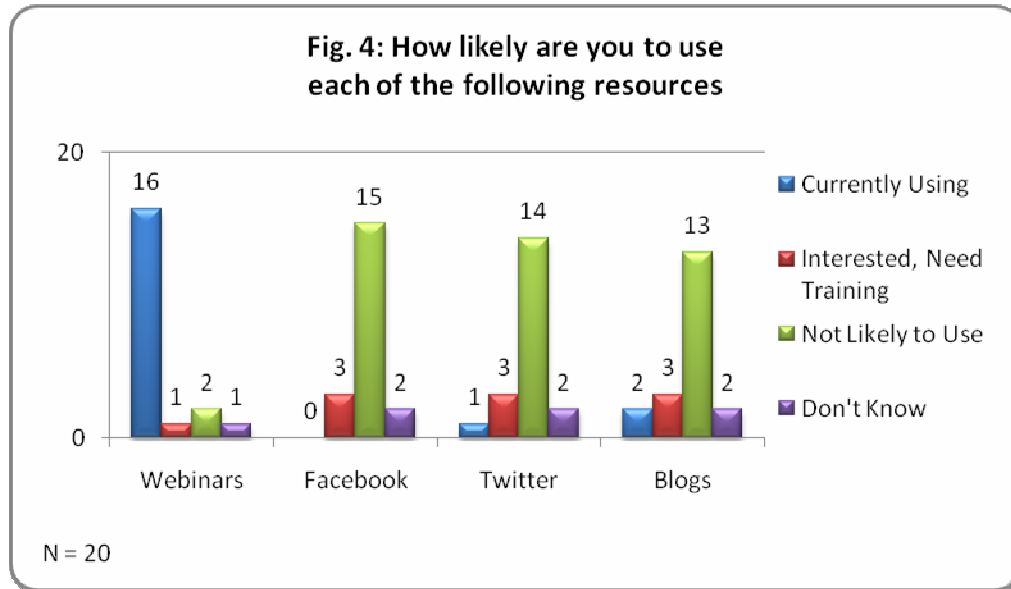
Yr 2 Annual Meeting Summary: 12 agreed, four were neutral, and none disagreed.

Comments

- ❖ I feel in the dark about what progress is being made.
- ❖ I intend to read these before the next advisory council meeting but have not had time to do so now.
- ❖ I was not aware that these reports existed. I will review them on line. An email to all stakeholders might help let people know when new reports or materials are posted. If this occurred previously, I did not receive it, or don't recall it.
- ❖ Need to review year 1 evaluations
- ❖ The reports which have been issued have all been comprehensive and informative. I can't specifically evaluate each of the above reports.

Alternate Methods for Communication

The NEGC is reviewing multiple methods for improving communication with our stakeholders. How likely are you to use each of the following resources?



Webinars: Sixteen were currently using, one was interested, two were not likely to use, and one indicated they didn't know if they would use it.

Facebook: None were currently using, three were interested, fifteen were not likely to use, and two indicated they didn't know if they would use it.

Twitter: One was currently using, three were interested, fourteen were not likely to use, and two indicated they didn't know if they would use it.

Blogs: Two were currently using, three were interested, thirteen were not likely to use, and two indicated they didn't know if they would use it.

Comments

- ❖ Direct e-mail (3)
- ❖ Blogs are a good way to promote discussion and obtain feedback
- ❖ Listserves
- ❖ Programmed self-instruction modules which can be done at the learner's convenience
- ❖ Such sites [reference to webinars] are not fully accessible by some community stakeholders.

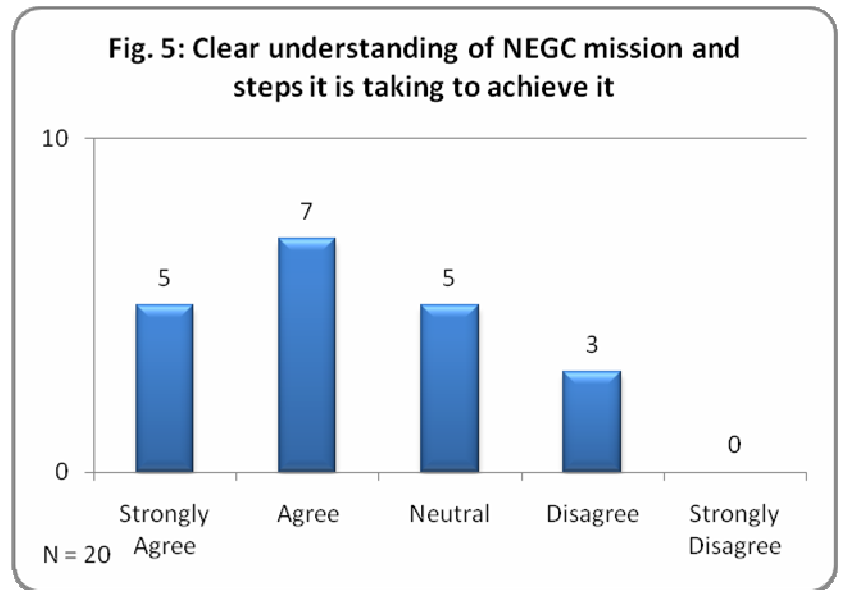
Understanding NEGC Mission

I have a clear understanding of the NEGC's mission and the steps it is taking to achieve that mission.

Twelve members agreed, five were neutral, and three disagreed.

Comments

- ❖ More regular updates would be helpful
- ❖ Understand only parts that I am directly involved in
- ❖ Mission is clear, steps less so.



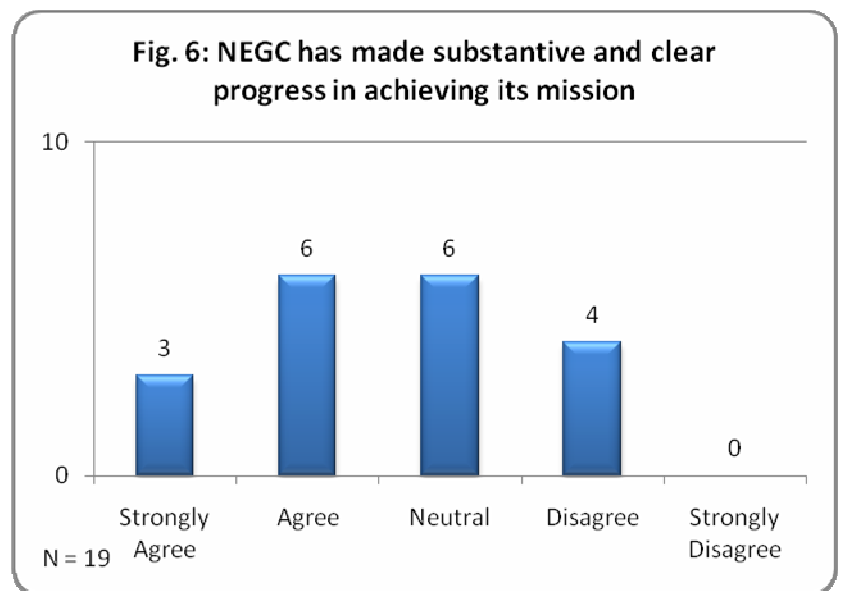
Substantive and Clear Progress in Achieving Mission

The NEGC has made substantive and clear progress in achieving its mission.

Nine members agreed, six were neutral, and four disagreed.

Comments

- ❖ Medical home seems to be making some progress. Innovative grants also seems very positive. Beyond that I am not certain of what is happening.
- ❖ More regular updates would be helpful
- ❖ Unsure of how I fit in with NEGC as a stakeholder. I am in NYMAC.



Selected Comments from Advisory Council, Collaborative Council, and Workgroup Members

Although only a limited number of responses were available from each of the organizational bodies, a number of comments were provided by individuals across these groups that are of value for all participants to review. Some of the issues raised in individual group comments focused on: a need for clarity within groups re: what was happening, limited understanding how groups were collaborating with other groups and the challenges encountered, recognition of collaborative activities within groups, a need for regular meetings, a need to better integrate data as a part of documenting improvements, better understanding of what supports are provided at the work group level, and need for greater clarification about progress. In addition to these

comments, more substantive feedback was provided across groups for survey questions related to the top three group strengths, challenges, and needed supports from the NEGC.

Strengths of the Groups

- ❖ Collaborative Spirit (5): participation in grant process, approach of members
- ❖ Commitment (4): to similar goals, mission/vision
- ❖ Leadership (4): John Moeschler
- ❖ Administrative Support by Karen and Amy (3):
- ❖ Experience of members (3)
- ❖ Communication and open discussion (3)
- ❖ Varying viewpoints / ideas (3)
- ❖ Clear objectives (2)
- ❖ Common mission (2)
- ❖ Other
 - Coordination with national groups
 - Diversity of membership
 - Efficient meetings with sufficient flexibility to have important discussions
 - Input on consumer and other issues
 - Investment in the concept of LTFU
 - It is focused on the work at hand and serves to remind us of our progress or failure thereof

Challenges Identified Within Groups

- ❖ Time for greater involvement (9)
- ❖ Member interaction (6): diversity, developing trust, individual personalities, tension between members, personality conflicts, negativity by some
- ❖ Utilization of health information technology (5): confidentiality issues involved in transfer, lack of interoperable HIT, lack of buy in on the part of individual states to LTFU due to HIPAA and other factors, availability of states legal/privacy consultants, need for coordination among centers and electronic medical records
- ❖ Resources (4): available funds to actually accomplish needed objectives, funding for data entry, relatively small funding for WG's lead to all leaders and members having little time committed to specific work and products related to WGs and NEGC
- ❖ Length of time between meetings (3): may result in project slipping to "back burner" (although I'm not suggesting that frequency of meetings should increase)
- ❖ Geographical limitations and limitations on travel (3): distance, limitations on travel, need for face to face meetings
- ❖ Other
 - Getting IRB approval for projects
 - Leadership with adequate time and resources to communicate, solicit input and engage the membership.
 - More specialty focused vs. PCP/Specialty collaboration
 - Coordination of individual work groups
 - Focus of objectives
 - Getting measurement integrated into the work to demonstrate meaningful progress
 - Tested strategies

Support Roles of the NEGC

- ❖ Continue to remind me about due dates (5)
- ❖ Help with writing--grants, papers, documents, IRB applications, etc. (3)
- ❖ Technical support (3)
- ❖ Better communication (2)
- ❖ Finding new opportunities (2): Link me up with others interested in the same topics as I am
- ❖ Leadership (2)
- ❖ Other
 - I am more of a recipient of information at this point in time - I have no active role since the focus has been on clinical/office/hospital initiatives
 - Provide greater support to the workgroup leaders or suggest co-chairs for greater effectiveness.
 - Staff could take an active, ownership role in assuring success by WGs.
 - To establish greater transparency in decision making and engage others in that process.
 - To what extent can the staff of NEGC provide TA to organizations trying to improve access to and quality of genetic health care services?

Other Comments Provided by All NEGC Stakeholders

Respondents also had the opportunity to complete an open survey question concerning any other feedback they had for the project. Comments reflected on the overall impact of the project and the work of individual staff, the positive interactions of the NERGG and NEGC conference, as well as recommendations around more frequent communication, greater involvement in decision making, and outreach to stakeholders.

- ❖ As a member of the advisory committee I feel my time is very well spent when the NEGC convenes annual/other meetings. Meetings are always thoughtfully planned to create a balance of reporting on progress and garnering input on activities and issues. Amy's updates are thorough and informative, and help me keep up to date on the project between meetings, while Peter's formal evaluation reports clearly indicate the substantial progress the NEGC has made in its first two years. I appreciate the opportunity to participate in this initiative.
- ❖ Great job!
- ❖ Have only attended on work group meeting; missed the phone call in March due to vacation; plan to attend next phone call. So don't have too much to base this on.
- ❖ I do think that last years NERGG Annual Conference which involved the NEGC was a very positive thing. The presentations (Medical Home) which were part of the meeting, along with poster sessions which highlighted the small innovative grants were very very strong. The opportunity to collaborate around this event was wonderful. We need more opportunities like this.
- ❖ I would suggest more frequent updates sent as emails. This could be an email that something new has been posted or a workgroup or committee highlight.
- ❖ The NEGC is in a unique position to improve on a regional collaborative that possesses strengths, yet still has improvements needed. More inclusive decision making, and greater transparency is needed in the administration of the effort, as well as more regular communication and outreach to key stakeholders who are looking to become involved but who do not feel part of the process. Efforts in that area will go far to set the objectives for future years and will stimulate greater engagement by those who can help define and achieve the regional mission. Thanks for the opportunity to provide feedback to help build a great regional collaborative in the future.

Recommended Areas of Follow-Up

The data collected in this year's survey, while somewhat limited in terms of representation from the full membership in the NEGC, does point to some needed areas for follow-up by project staff as well as stakeholders.

- 1) In reviewing multiple responses, substantial feedback was received indicating that a number of individuals were not familiar with key aspects of the NEGC (mission, availability of evaluation reports, what happens between meetings, etc.). Given that this has been an ongoing challenge cited in previous evaluation reports of the NEGC, continued emphasis on supporting existing communication efforts as well as broadening communication strategies to keep members up to date on the NEGC's mission, activities and accomplishments is recommended.
- 2) Create new resource maps for the website: available financial resources, resources for families, location of support groups, metabolic clinics, and other specialists serving patients with genetic diseases.
- 3) Update spotlight projects section of website, with emphasis on successful collaborations between primary care and genetic clinics, work of individual workgroups, and potentially successful projects from other regions. Quarterly, send out a request for members to identify any new projects which should be highlighted on the website in order to assure that information is kept current.
- 4) A number of members indicated they were either neutral or disagreed with the notion that the NEGC appropriately engages with service providers, decision makers and consumers. The NEGC should continue discussions around broadening the service provider/decision maker and consumer base - develop concrete plans with objectives to identify how the NEGC will grow in Year 3 in terms of membership and what steps will be taken to ensure that each participating group/individual has access to current information that keeps them connected with the collaborative.
- 5) Prepare to provide additional supports around technology use. While most of those responding to the survey indicated familiarity with Webinars, most indicated they were not likely to use Facebook, Twitter, or Blogs. If substantial investments in these areas are made it may be helpful to provide the membership with additional and clear information on why the use of the new technology will be important to them (and thereby the success of the NEGC), how members can access and manage the information, and how members could participate in sharing their own information. Also, as suggested by one respondent, some information made available via webinar should be made available in alternative formats (for community stakeholders without high speed, or any, internet connections).
- 6) Monitoring of group and individual dynamics. While differences in opinion are going to exist in any broad-based effort, it is important for all stakeholders to have a common understanding of where we have been as a group, where we are and where we are going. A number of individuals cited concerns about potential conflicts arising between members or how individual personalities can come into conflict with the mission of each group. Project staff and work group chairs should pay attention to these dynamics, and ensure that they take the time to provide support / clarification to those involved as soon as issues arise prior to larger issues developing. This is particularly critical given the fact that some groups do not meet on frequent intervals and continuing challenges cited by members concerning a lack of frequent communications.
- 7) Have an open discussion around issues raised by respondents, including:
 - ❖ How else can greater support be provided to workgroup leaders? Would the creation of co-chairs increase effectiveness of the workgroups?

- ❖ Should project staff take an active, ownership role in assuring success by WGs? What would this look like?
- ❖ How can greater transparency in decision making be established? How can the NEGC better engage others in that process?
- ❖ To what extent can the staff of the NEGC provide TA to organizations trying to improve access to and quality of genetic health care services? How broad of a support should (can) be given? What are the limitations with existing resources?