

New England Genetics Collaborative

Results of the Stakeholder Survey for Project Year Three

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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 Four. To facilitate this feedback, the NEGC conducts an annual survey of its partners to identify concerns, document how the project is doing, and solicit suggestions for improvement. Seventy-two email invitations were sent out between September and October 2010 to stakeholders of the New England Genetics Collaborative (NEGC). Of these, 42 (58%) provided responses.

Since last year's report, there was slight improvement in two important areas. When asked whether they had a clear understanding of the NEGC's mission, 67% agreed (vs. 60% in 2009). Concerning whether the NEGC had made substantive and clear progress in achieving its mission, 56% agreed (vs. 47% previously). Feedback on the project's evaluation reports was generally positive, with 48% to 71% of respondents indicating that each of the reports helped them understand the progress and challenges of the NEGC. Respondents suggested a wide range of information that would be useful on the NEGC's new website, as well as in future updates provided by the NEGC.

Feedback from the Advisory Council was higher this year, with 13 members participating. Most participants felt that there was a good spirit of cooperation, that meetings were well run, that the Regional Coordinating Council (RCC - made up of NEGC project staff) provided excellent support and responded effectively to questions, and that the Advisory Council was achieving its main objectives. The number of responses from two workgroups (Dissemination, Education, & Marketing and Transition) were high enough to include in this year's report. Fifty percent or more of these two groups rated the following areas as good: collaboration and cooperation across meetings, that meetings were well run, that the RCC provided excellent support and that the workgroup was achieving its main objectives. There was less agreement in both groups around the effective use of data on the group's outcomes.

When asked about the strengths of the collaborative, several common themes emerged across survey respondents, highlighting: leadership capacity, collaborations, diversity of respondents, project focus, skills, administrative supports, commitment, and other.

Concerning some of the obstacles faced, the most frequently cited challenge was the potential for competing interests to tie up resources, the need for better clarity around accomplishments, greater diversity among membership, need for better communication (particularly across groups), better staffing and collaboration, as well as limited diversity, funds, and time.

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 meetings, reports, tracking objectives), identifying new collaboration opportunities and other.

Results are separated into: context of the report (p.2), survey results (p.3), and recommended areas for follow-up (p.14). For ease of reading, duplicate open comments 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 2010 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.

Several steps were taken this year to improve participation in the survey. First, a formal letter was sent out by Drs. Moeschler and McClain inviting people to participate in the survey. Second, respondents were entered into a raffle drawing for one of two \$25 gift certificates. Third, a final survey reminder was sent via regular mail prior to the close of the survey process. As a result of these steps, survey participation increased considerably. Of 72 invitations sent, 42 (58%) responded to the survey. Perspectives represented include: 16 Clinicians, 13 Public Health, 12 Service Providers, 11 Researchers, 11 State Agencies, 5 Educators, 5 Families, and 4 Other. No one indicated that they were participating as a consumer representative. Note that some individuals may represent multiple perspectives.

Limitations

The information provided in this report provides a partial indication of stakeholder perceptions after three years of the project's activities. With 58% of known stakeholders responding, many perceptions on project progress remain absent, particularly from some of the project workgroups and 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

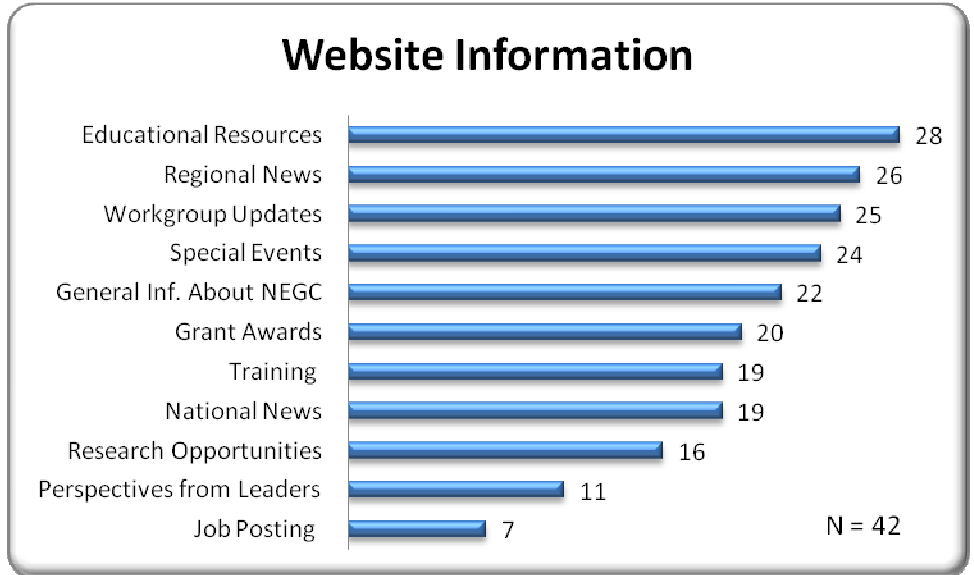
To help protect the anonymity of respondents, reporting of the rating data (Strongly Agree – Strongly Disagree Scales) has been suppressed in cases where less than five of the members of a particular group responded to the survey. Comments have been aggregated and are provided in cases where feedback would provide the broader group with potentially useful information. Detailed summaries are available only for those questions which were asked of all stakeholders, members of the Advisory Council, as well as the DEM and Transition Workgroups.

Survey Results for All Stakeholders

NEGC Communication and Interaction with Partners

What kinds of information should the NEGC incorporate into the new website?

Out of 42 respondents, 20 or more indicated: educational resources, regional news, workgroup updates, special events, general information about the NEGC, and grant awards. Ten to 19 indicated: training, national news, research opportunities, and perspectives of leaders in the field. Seven requested information on job postings.



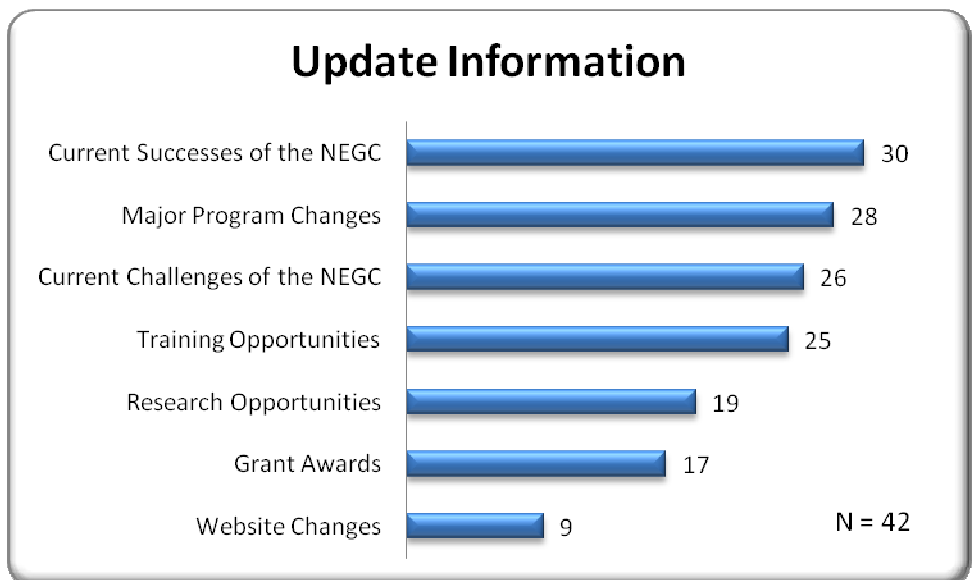
Comments

- ❖ Post grant opportunities for support services for specific diseases as well as for national grant opportunities for newborn screening

How often should the NEGC provide updates on progress? What kinds of information should be provided?

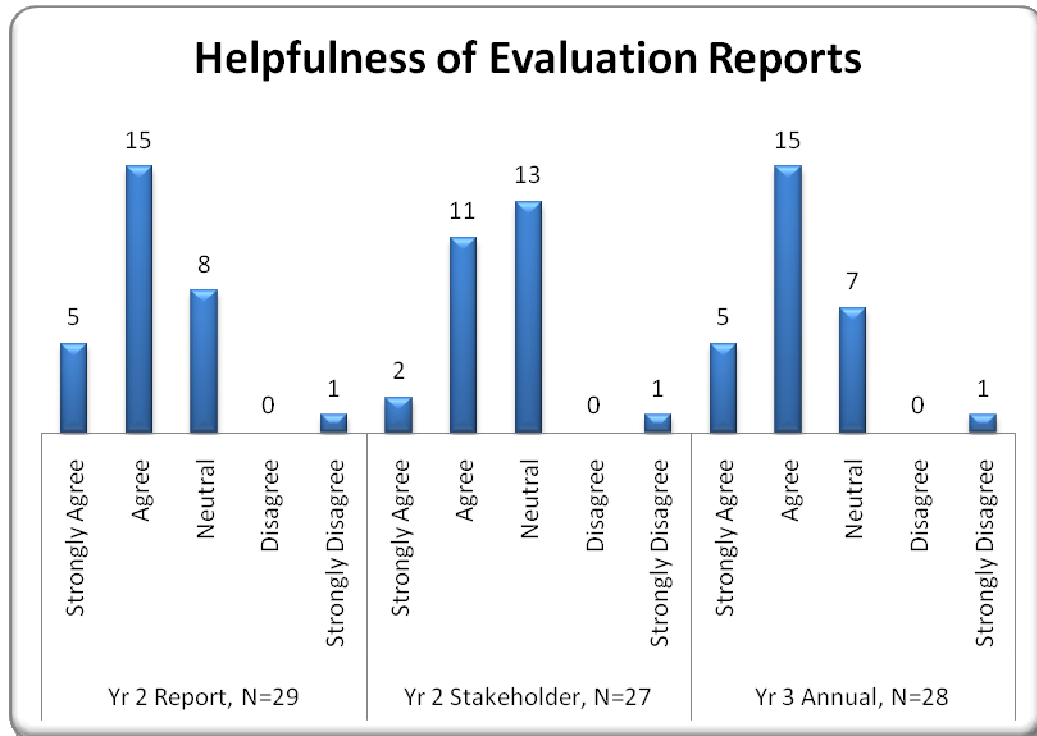
A strong majority (33 of 42 respondents) indicated a preference for quarterly updates. Only 7 wanted information monthly and 2 wanted it yearly.

In terms of the types of information that people looked for, 20 or more indicated: current successes of the NEGC, major program changes, current challenges of the NEGC, and training opportunities. Slightly under 20 requested information on research opportunities and grant awards. Nine wanted to be kept informed of major website changes. Other requests for information included: an eblast with notices about new information available on the web and highlights of successful endeavors, a personal feature focusing on



successful outcomes of program implementation or overcoming a barrier leading to positive change, reports on various workgroup projects and programs, and information on opportunities for participation.

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



Yr 2 Evaluation Report (N=29): 69% agreed, 26% were neutral, and 3% disagreed.

Yr 2 Stakeholder Report (N=27): 48% agreed, 48% were neutral, and 4% disagreed

Yr 3 Annual Evaluation Report (N=28): 71% agreed, 25% were neutral, and 4% disagreed.

Comments

- ❖ Provide notification when available (2)
- ❖ Have not seen the reports (2)
- ❖ Shorten length of year end reports, 1 page executive summary

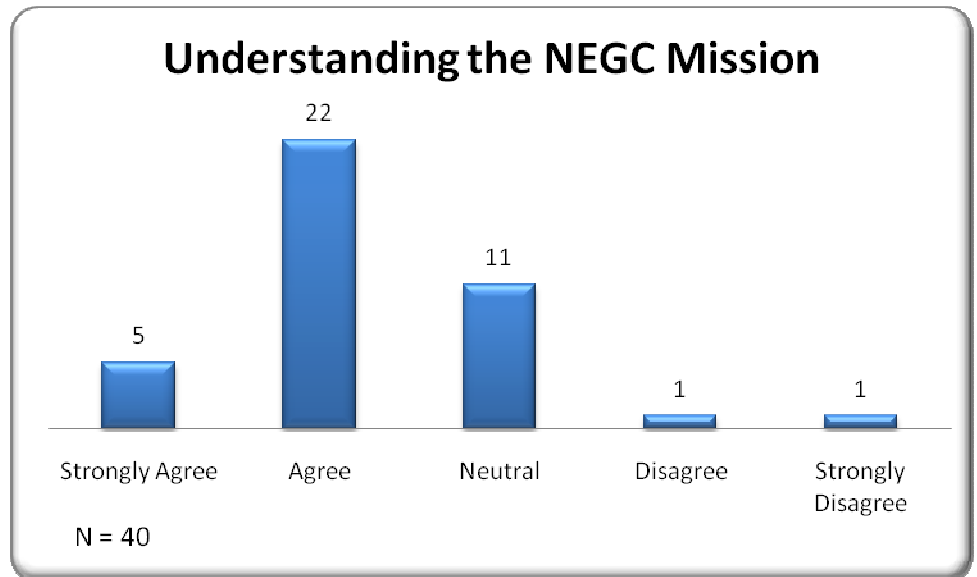
Understanding Organizational Mission and Impact

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

Out of 40 responses, 67% agreed, 27% were neutral and 5% disagreed.

Comments

- ❖ Clear re:mission, but not activities.

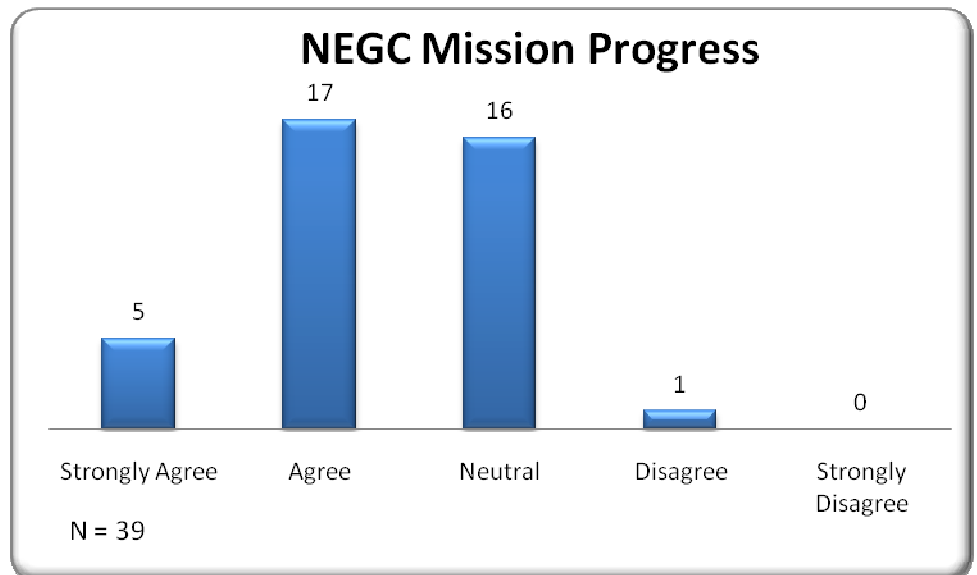


Do stakeholders agree that the NEGC has made clear and substantive progress on achieving its mission?

Out of 39 responses, 56% agreed, 41% were neutral and 3% disagreed.

Comments

- ❖ Unsure of progress





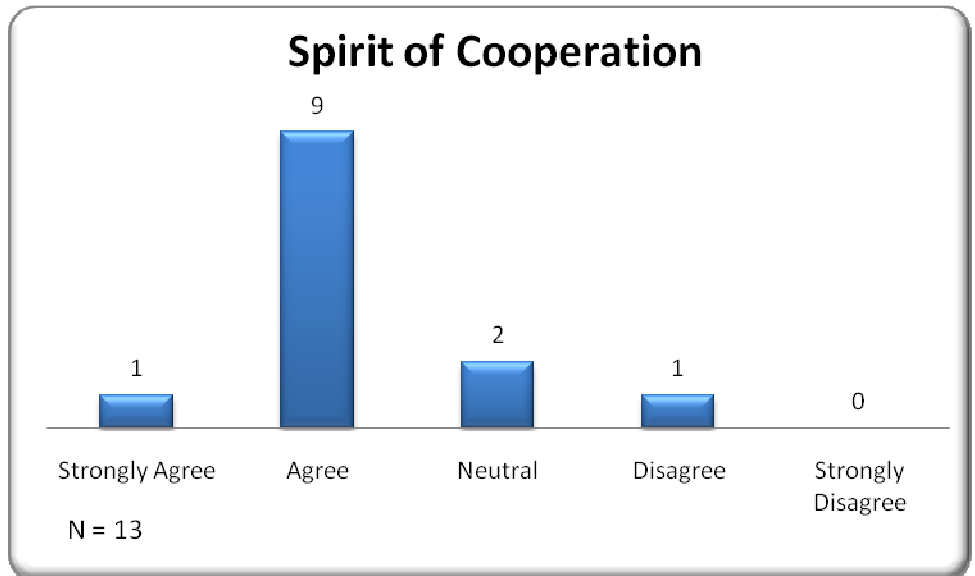
Survey Results for the Advisory Council

Is there a spirit of cooperation and collaboration among Advisory Council members.

Out of 13 responses, 77% agreed, 15% were neutral, and 8% disagreed.

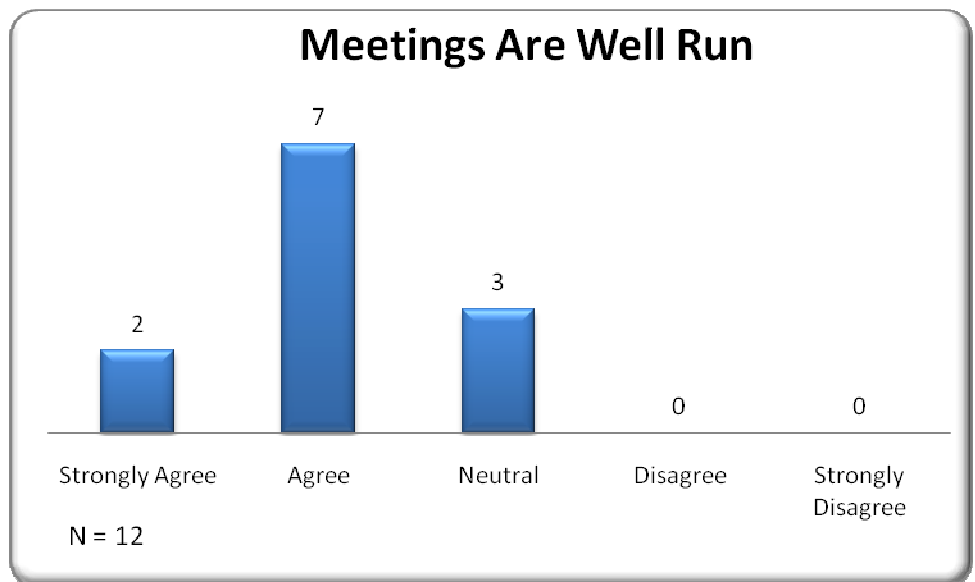
Comments

- ❖ Yes, but not consistently (2)



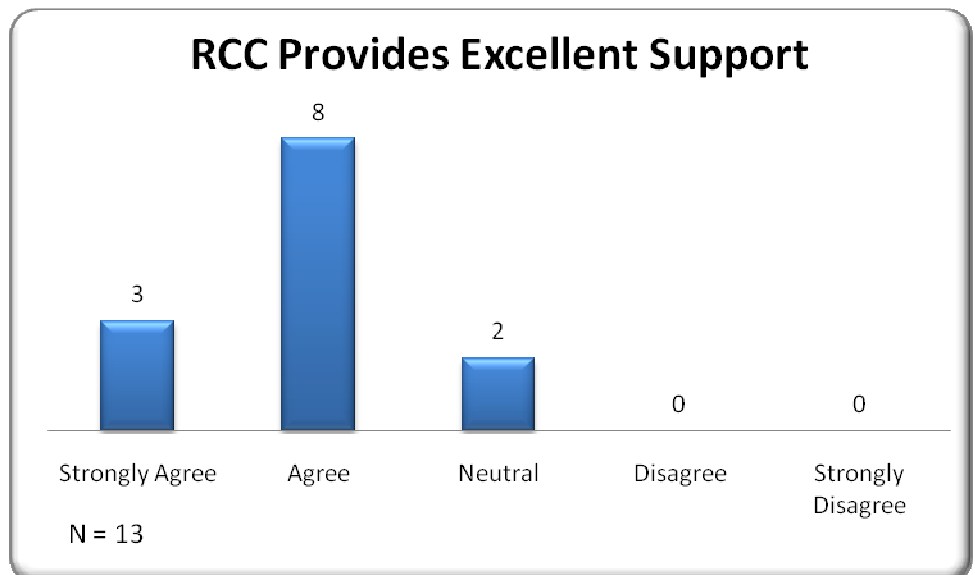
Are meetings are well run and productive?

Out of 12 responses, 75% agreed and 25% were neutral. No one disagreed.



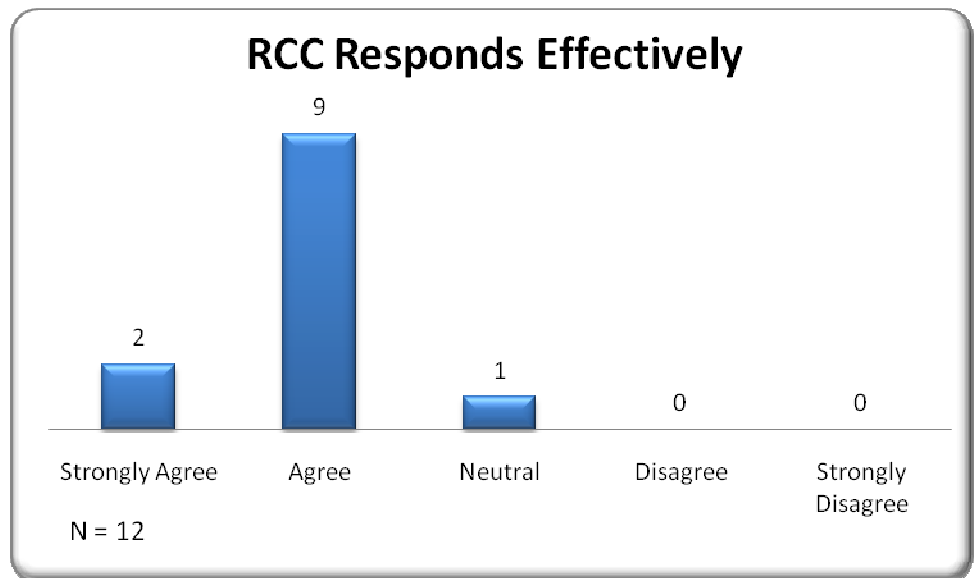
Does the Regional Coordinating Center (staffed by John Moeschler, Monica McClain, and Karen Smith) provide excellent support to the Advisory Council?

Out of 13 responses, 85% agreed and 15% were neutral. No one disagreed.



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

Out of 12 responses, 92% agreed and 8% were neutral. No one disagreed.

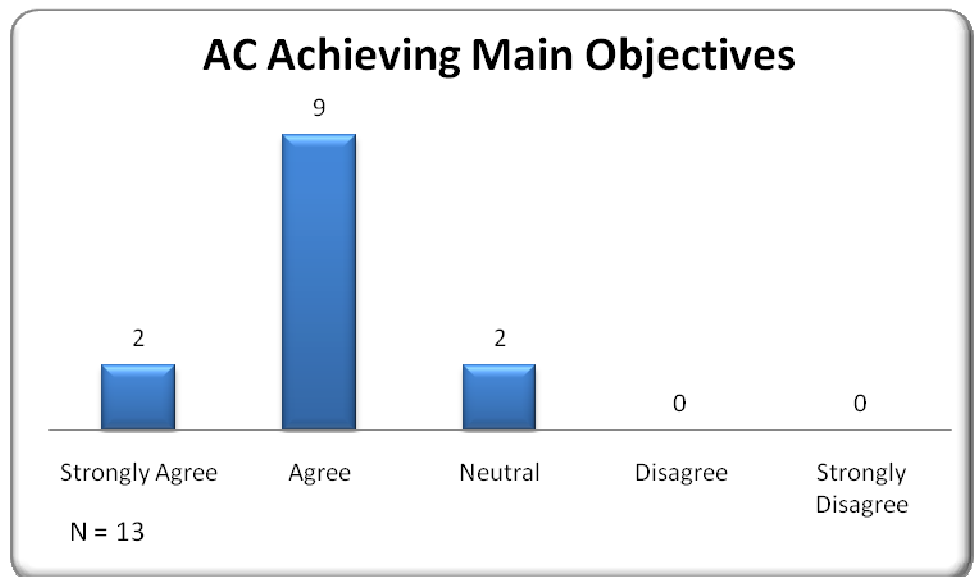


Overall, does it appear that the Advisory Council is achieving its main objective of providing guidance and support to the NEGC to address its mission.

Out of 13 responses, 85% agreed and 15% were neutral. No one disagreed.

How often should the Advisory Council meet?

Out of 12 respondents, 67% stated semi-annually, 25% yearly, and 8% quarterly.



What are the strengths of the Advisory Council?

- ❖ Diversity of perspectives (7)
- ❖ Commitment (2)
- ❖ Networking / collaboration opportunities (2)
- ❖ Other (6): family / consumer participation, providing feedback to NEGC leadership, expertise, supporting innovation and the grants process, learning about advances in the field

What are the main obstacles faced by the Advisory Council?

- ❖ Availability to participate (5)
- ❖ Limited involvement (2)
- ❖ Other (4): limited diversity, travel restrictions by state, need for more consumer representatives and clear objectives for the council

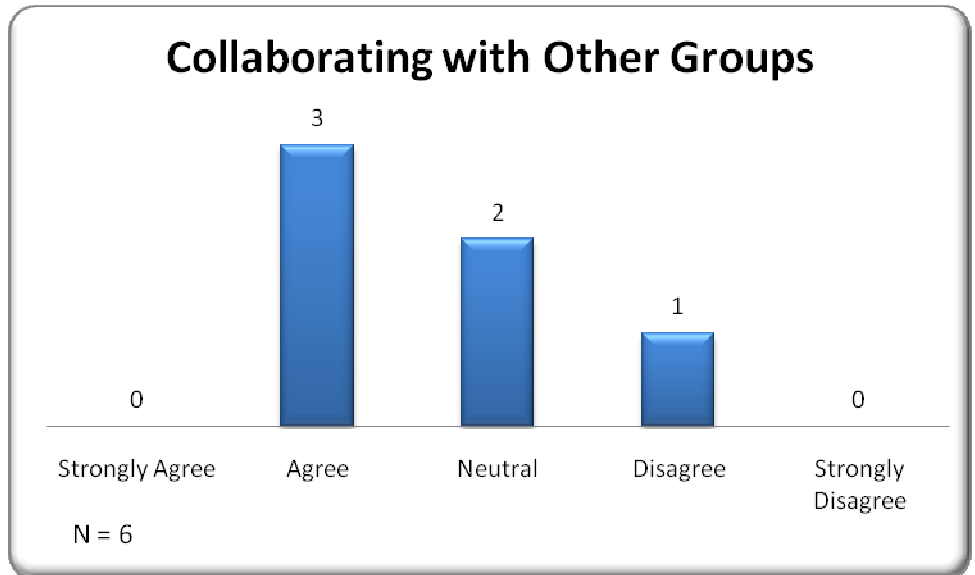
Survey Results for the Dissemination, Education, and Marketing Group

Does the workgroup effectively collaborate with other relevant groups?

Out of 6 responses, 50% agreed, 33% were neutral, and 17% disagreed.

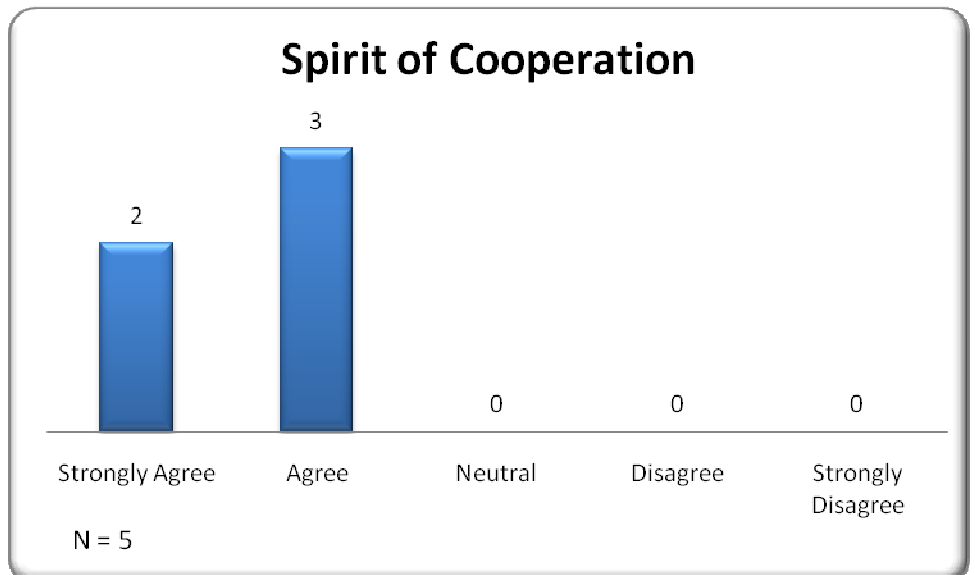
Comments

- ❖ Except for focus groups with schools, limited collaboration with other relevant groups.



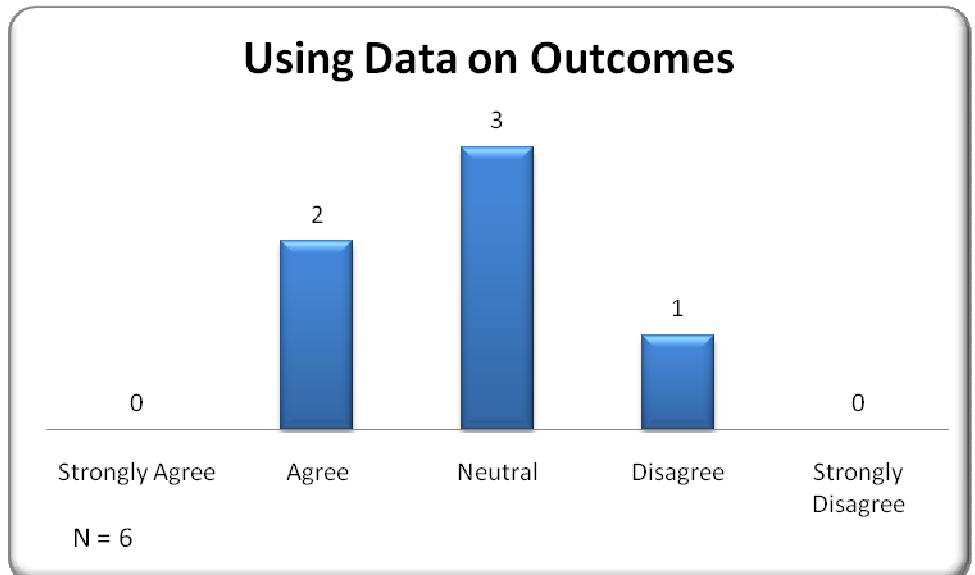
Is there a spirit of cooperation and collaboration among working group members?

Out of 5 responses, 100% agreed.



Does the workgroup effectively use data on outcomes to keep improving?

Out of 6 responses, 33% agreed, 50% were neutral, and 17% disagreed.

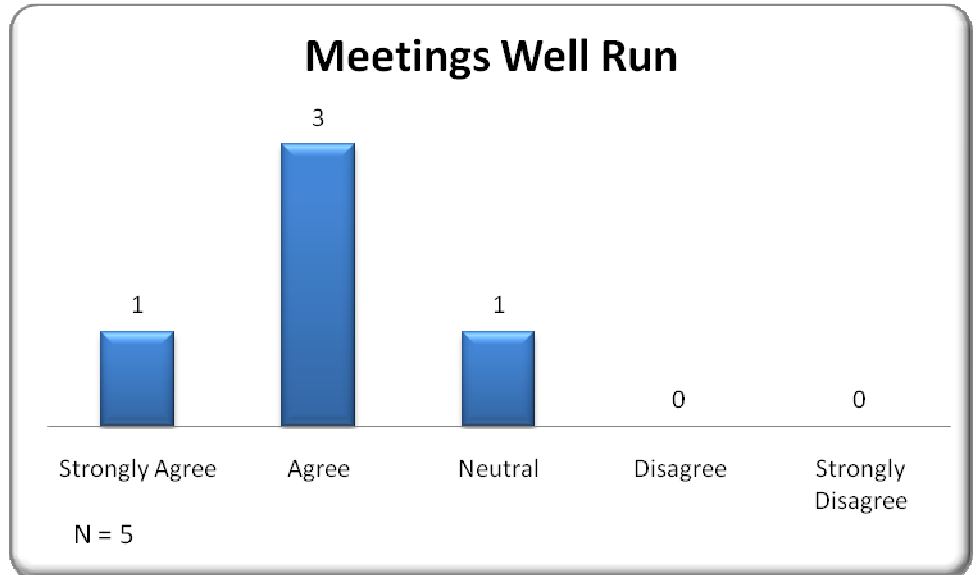


Are meetings well run and productive?

Out of 5 responses, 80% agreed and 20% were neutral. No one disagreed.

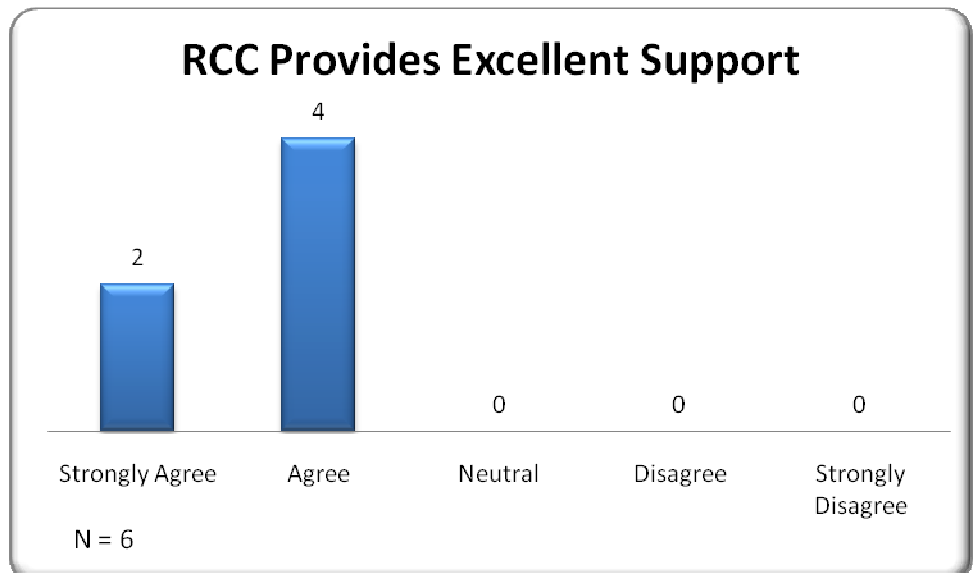
Comments

- ❖ Difficulty attending meetings
- ❖ Mostly done by conference call, one face to face.



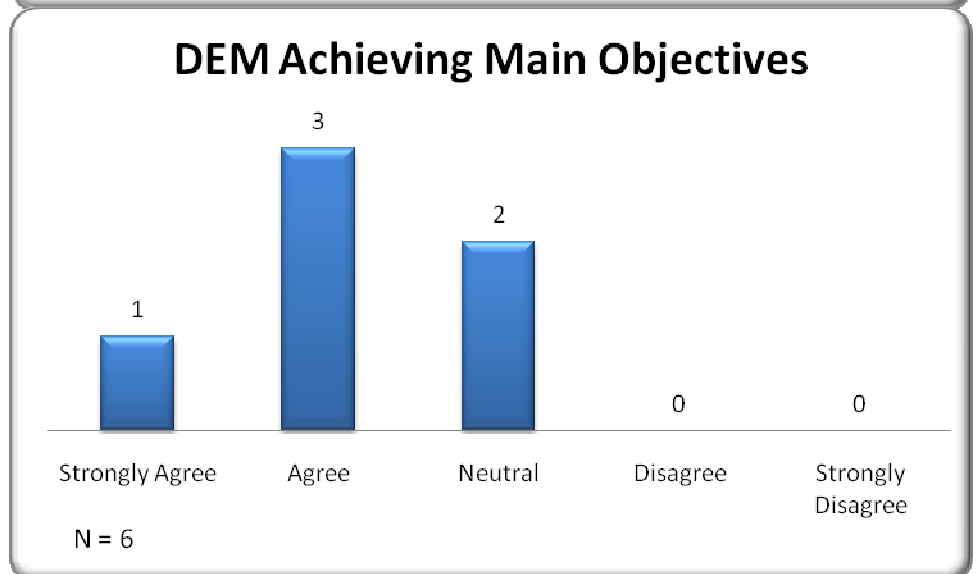
Does the Regional Coordinating Center (staffed by John Moeschler, Monica McClain, and Karen Smith) provide excellent support to the workgroup?

Out of 6 responses, 100% agreed.



Overall, is the workgroup able to achieve its main objectives?

Out of 6 responses, 67% agreed and 33% were neutral. No one disagreed.



What are the strengths of the group?

- ❖ Commitment (2)
- ❖ Goals and objectives (2)
- ❖ Other (2): interest of members, representation of multiple states

What are the obstacles faced by the group?

- ❖ Lack of paid time for staffing support (2)
- ❖ Time for participation (2)
- ❖ Other (2): distance between members and lack of face to face time

What can the NEGC do to help?

- ❖ Administrative support (5)
- ❖ Other (5): collaboration building, more mini grants, help prioritizing projects, salary support, technical support

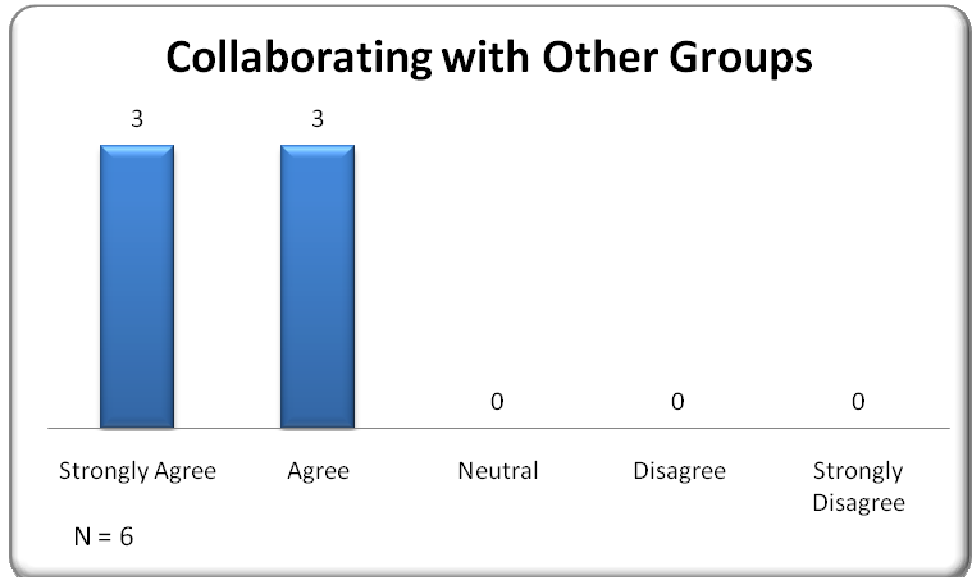
Survey Results for the Transition Group

Does the workgroup effectively collaborate with other relevant groups?

Out of 6 responses, 100% agreed.

Comments

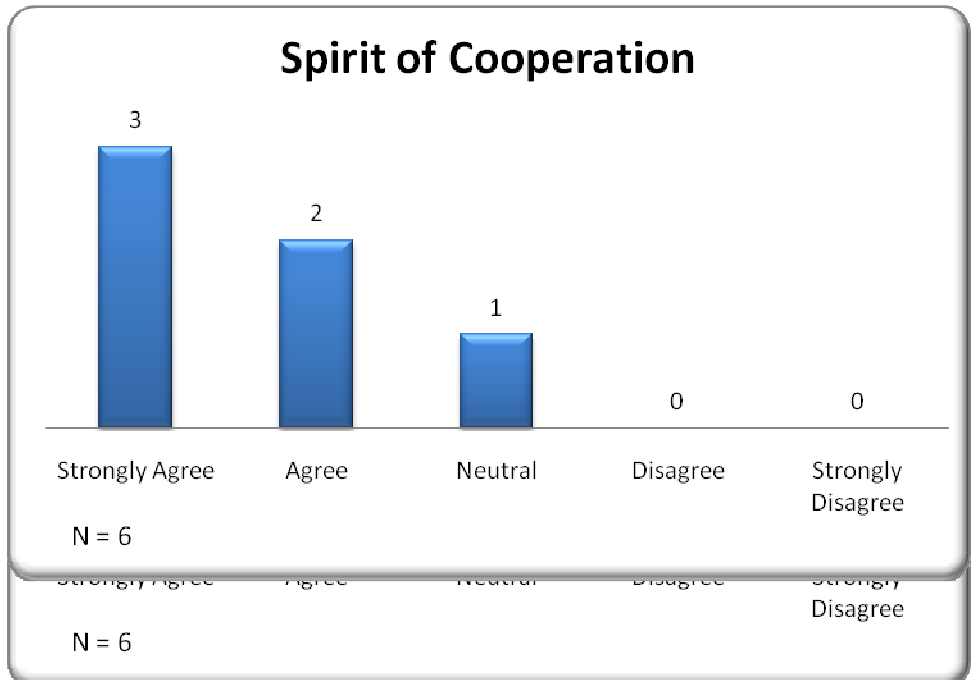
- ❖ The transition group has partnered with medical home.



Is there a spirit of cooperation and collaboration among working group members?

Out of 6 responses, 83% agreed and 17% were neutral. No one disagreed.

- ❖ Involvement primarily limited to monthly conference calls



Does the workgroup effectively use data on outcomes to keep improving?

Out of 6 responses, 17% agreed, 67% were neutral, and 17% disagreed.

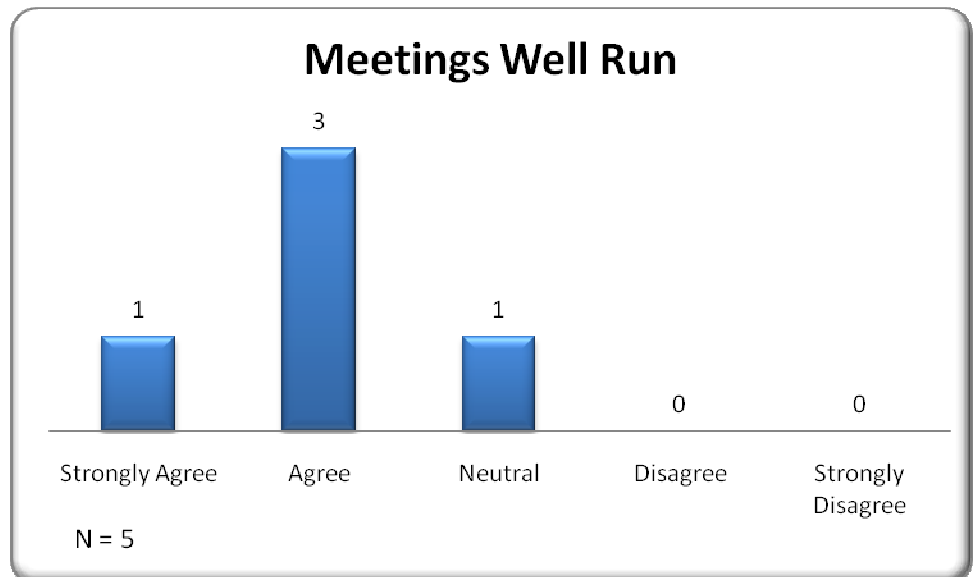
- ❖ We are weak in this area (2)

Are meetings well run and productive?

Out of 5 responses, 80% agreed and 20% were neutral. No one disagreed.

Comments

- ❖ I cannot attend most meetings
- ❖ They are mostly conducted by conference call. One face to face in conjunction with the Annual meeting.



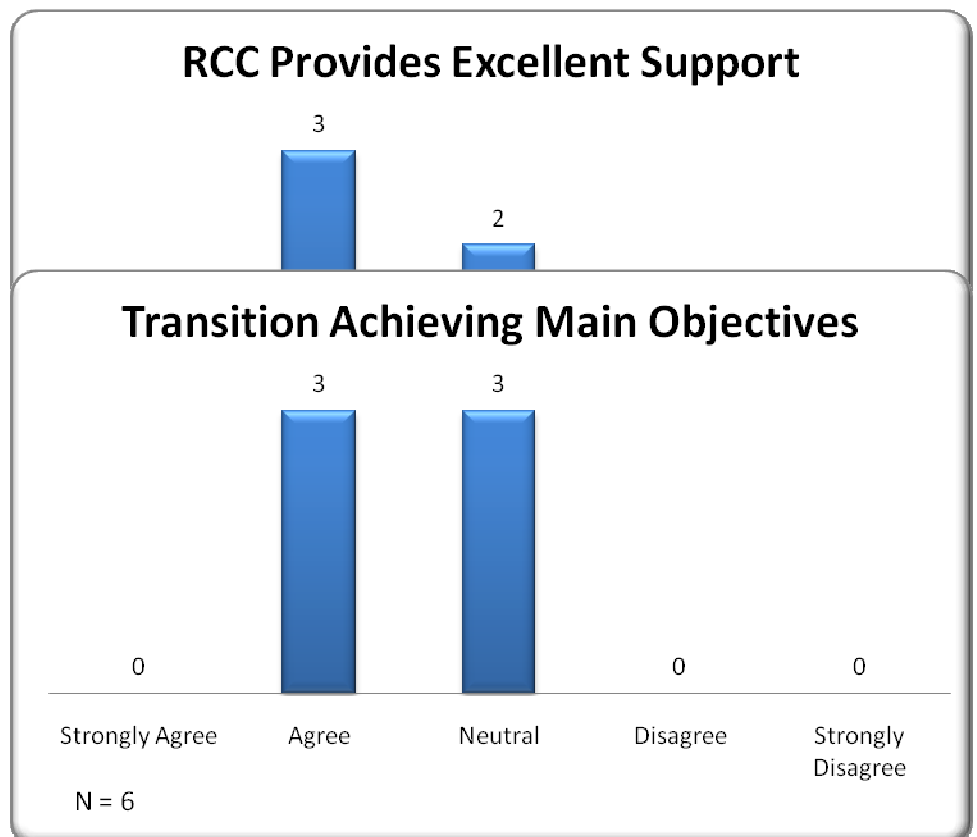
Does the Regional Coordinating Center (staffed by John Moeschler, Monica McClain, and Karen Smith) provide excellent support to the workgroup?

Out of 6 responses, 67% agreed and 33% were neutral.

Comments

- ❖ Karen has been amazing

Overall, is the workgroup able to achieve its main objectives?



Out of 6 responses, 50% agreed and 50% were neutral. No one disagreed.

What are the strengths of the group?

- ❖ Leadership (3)
- ❖ Collaboration (2)
- ❖ Dedication (2)
- ❖ Other (2): participation in national interest group, broad perspectives

What are the obstacles faced by the group?

- ❖ Need better clarity around accomplishments (4)
- ❖ Greater diversity among membership (3)
- ❖ Other (2): only meet by phone, lack of sustainability after HRSA grant

What can the NEGC do to help?

- ❖ Administrative (3)
- ❖ Collaboration building (2): CT Newborn Screening Program Advisory Committee, impact of different disciplines on newborn screening process
- ❖ Other (3): help focus on a coherent project, address conflict with other meetings (metabolic consortium), discuss how different disciplines contribute to the NEGC goals and objectives

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

Although only a limited number of responses were available from the remaining groups (Collaborative Council, Quality Assurance, Quality Improvement, Long Term Follow Up, and Medical Home), a number of comments were provided by individuals across these groups that are of value for all participants to review. Following is a breakdown of themes drawn from stakeholder responses to questions on group strengths, challenges and needed supports from the NEGC.

Strengths Identified Across Groups

- ❖ Leadership (8)
- ❖ Collaborations (4)
- ❖ Focus of the project (3)
- ❖ Participant skills (3)

- ❖ Administrative supports (3)
- ❖ Interest areas (2)
- ❖ Other (5): commitment, diversity, honesty, innovation, open discussions on emerging regional / national topics

Challenges Identified Across Groups

- ❖ Competing interests (4)
- ❖ Need for better communication (3)
- ❖ Little contact concerning group (3)
- ❖ Limited diversity (2)
- ❖ Limited funds (2)
- ❖ Limited time (2)
- ❖ Staffing (2)
- ❖ Building effective collaborations (2)
- ❖ Other (5): somewhat centralized at UNH, lack of consumer involvement, geography, sustainability after the HRSA grant, variety in individual state ability to follow through with goals

Support Roles of the NEGC

- ❖ Administrative (8)
- ❖ Collaboration opportunities (3)
- ❖ Not sure what support is provided (2)
- ❖ Other (5): role of different disciplines in NEGC goals, hold discussion on public policy in Region 1 states, support current workgroups without creating new ones with potentially competing projects, continue project support for QI efforts, provide training

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. Shared comments reflected on critical and positive perceptions on the NEGC, as follows:

- ❖ Critical
 - Do not have a good sense of activities of the overall NEGC
 - Administrative processing of the subcontracts needs considerable improvement.
- ❖ Positive
 - Enjoy coming to the annual meeting (2)
 - The project is extremely important, and I believe much energy and skill has gone into it thus far.
 - Thank you!

Recommended Areas of Follow-Up

The data collected in this year's survey represented a substantial improvement in NEGC stakeholder participation. While not fully representative of all identified partners, the 58% participation rate indicates strong representation of a range of viewpoints. In reviewing the available data, there are three recommended areas for further action by NEGC staff.

- 1) Despite the slight improvement in understanding of the NEGC's mission, there are still many individuals who are not familiar with many important components of the NEGC. This was represented in the proportion of individuals not understanding the mission of the NEGC, the limited responses concerning the evaluation report, the large number of neutral responses provided by respondents, and feedback provided by respondents concerning the large gaps in time between meetings. Given the ongoing challenge of this area, it is recommended that continued efforts focus on improving and broadening communication efforts by the NEGC at all levels (not only from management staff to other groups, but also within and across workgroups).
- 2) Improve utilization of data and outcomes tracking within groups. In both the DEM and Transition groups, there was limited understanding of the extent to which data and outcomes were linked to the overall objectives of each group. It may be helpful for all six of the workgroups to review current objectives with their membership to determine which data would be useful to collect (in terms of documenting both outcomes and the process efforts of the workgroup).
- 3) Have an open discussion around issues raised by respondents, including:
 - ❖ How can workgroup leaders foster cohesiveness not only within workgroups but across the major components of the NEGC?
 - ❖ How can the staff of the NEGC increase (and improve upon) opportunities for collaboration across current workgroups as well as between current workgroups and like-minded organizations not affiliated with the NEGC?