



Full Stakeholder Survey

Spring 2019

Institute on Disability/UCED



10 West Edge Dr. | Durham, NH 03834 | <https://www.negenetics.org>

Executive Summary

In May of 2019, the New England Regional Genetics Network (NERGN) sent an email invitation to 410 stakeholders asking that they complete the Annual Survey. Stakeholders were sent an additional follow-up email requesting their participation. Stakeholders include, but are not limited to, Steering Committee members, community partners, advocates, consumers, and providers. The Annual Survey sought to gain further insight into stakeholder involvement, perceptions about NERGN's adherence to mission, effectiveness of programming, and areas for improvement.

67% completion rate
9% response rate
58 surveys started
39 responses collected

Stakeholders identified to take part in this survey had varying degrees of participation in NERGN activities¹ with most having limited participation (e.g. only receiving emails, or participating in a single training). For the purposes of this analysis, respondents' answers have been split into two groups: consumer/ family member, and professional (primary care, researcher, public health, provider). It should be noted that almost half of all respondents indicated they were a part of multiple groups i.e. consumer, advocate, and genetic service provider. Of those who responded, seven were Steering Committee members, 16 identified as consumers or family members, and 23 were identified as professional². Not all respondents answered all questions³.

Overall, responses from the Stakeholder Survey suggest that NERGN is progressing to achieve the goals set forth by the mission. Notably, individuals who were more involved in NERGN's work over the last year were more likely to be satisfied with the progress made, have more ideas for improvement, and discuss more thoroughly any challenges they experienced within their own work.

Interestingly, within the two groups of respondents, the depth and breadth of consumers/family member responses surpassed those provided by the professional group. This factor could be the result of NERGN's increased involvement with Family Voices organizations throughout FY2018. The survey also suggests that NERGN has a dedicated and active Steering Committee. Half of all Steering Committee members responded to the survey and within the survey, members inquired about other opportunities to become further involved in the work.

Stakeholders indicated that NERGN's highest achievements of the year were in the education and training it provided. Another achievement was in collaboration among partners,

¹ Stakeholders who received this survey may or may not have participated in NERGN activities. In a change from previous years, we more than doubled our survey pool by including those who had participated in one or more training events but may not have had any other engagement with NERGN. If stakeholders did not participate in multiple activities it is less likely that they would have the buy-in to contribute to the survey. This variable may account for the low response rate as many stakeholders participated in one or fewer NERGN activities.

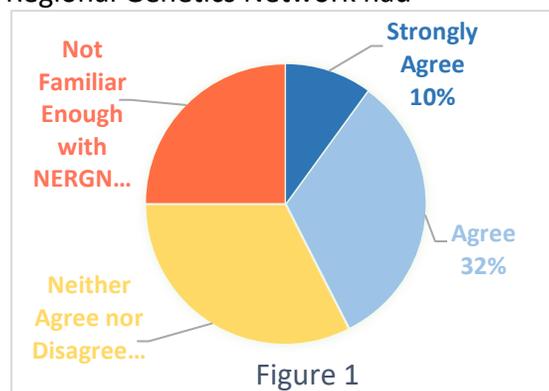
² Steering Committee members were not isolated as an individual group, but included in the total number of consumer/ family members or professional group (n=39).

³ Note: responses collected were fairly complete (n=39).

particularly with Family Voices organizations. Throughout the survey, stakeholders identified the importance of NERGN's role as a convener; this idea was discussed in both NERGN's existing and future work within the New England states among organizations, with families, and service providers. Respondents to the survey indicated that NERGN's biggest area for continued growth is within the development and dissemination of existing resources and materials. Other areas for improvement included on-going outreach, collaboration, and convening between stakeholder groups.

Mission

Stakeholders were asked about whether the New England Regional Genetics Network had made substantive and clear progress in achieving its mission over the last 12 months. In response, consumers/family members were more likely to Agree or Strongly Agree with NERGN achieving its mission. Within the professional group, respondents (n=17) indicated they were Not Familiar Enough with NERGN Activities or Neither Agreed nor Disagreed (see Fig. 1). The differentiation between the consumer/family and professional group is important because the consumer/family group is comprised of our closest working partners of the year, indicating that those closest to the work are more knowledgeable of the work and mission, and more satisfied with the progress than those who were less involved.



When asked to comment about the mission, consumers/family members discussed improvements made through increased outreach efforts. The professional group discussed more miscellaneous issues including further clarity needed to achieve mission, length of mission, improvements in telehealth, and "unsure".

Stakeholders were asked about which areas NERGN did especially well over the past 12 months and where they felt the most impact occurred. Consumer/family members (n=13) indicated that webinars and trainings were the most impactful throughout the year. The professional group (n=12) indicated that webinars, education, and connection with other organizations was done especially well within the last 12 months.

"Webinars were great. Loved that I could access them after by video, even if I wasn't available to watch live."

"Improve outreach. I've been looking for awesomeness like you for 12 years."

Stakeholders reflected that there were areas NERGN could have done things differently to better support its mission over the last 12 months. Consumers/family members indicated that additional outreach (i.e. events, newsletter) and connection with special population groups could have supported this. Another point made

Institute on Disability/UCED



was to clarify the “big picture” to stakeholders via a road map of activities or statewide conversations. Limited responses from the professional group (n=6) yielded answers that were primarily “unsure” or “not enough known” with one person suggesting outreach to groups with strong telehealth experience.

“It felt like things got stalled a few times. From my perspective, this made it harder for me to engage. I also think I might have appreciated a “picture” or schedule of the plan at the beginning of the year. That kind of road map can be very helpful to me to stay engaged and feel informed about the process.”

Communication and Participation in NERGN

Stakeholders were asked about the NERGN website, the helpfulness of resources, and which resources needed improvement.

Consumer/family member		Professional
Helpful	Q & A section on the website and GEMSS	Resources for families and providers, specifically, webinars, the Q & A section, and GEMSS
Needs Improvement	Material updates, more materials, space to discuss how Family Voices can provide support (i.e. peer to peer matches)	Increased dissemination or exposure within the community is needed as many did not know the materials existed

“I love the Q and A portions for families!! this should be disseminated and advertised more!! I had no idea it was there!”

“All useful, improve access by advertising available to key stakeholders outside of NERGN community.”

When stakeholders were asked about how they prefer to communicate, about half answered they prefer communicating through listserv and emails. About a quarter of those who responded indicated a preference for web-based presentations. One respondent commented that NERGN should consider the inclusion of inter-institution or organization representation to cross-disseminate information.

Stakeholders were asked what areas of program activity NERGN should consider to promote and improve the health and social well-being of those with inherited conditions in the region

Institute on Disability/UCED



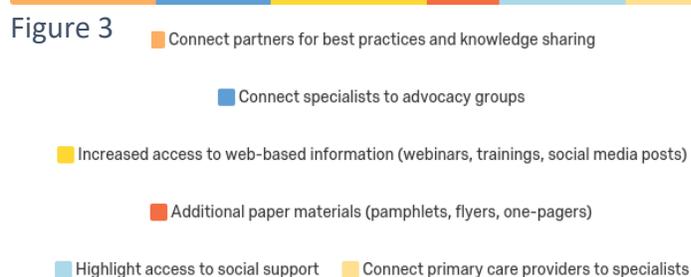
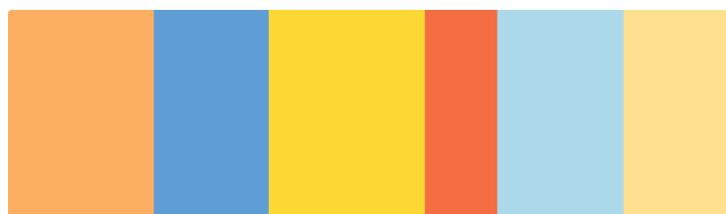
over the upcoming year. In response, consumers/family members had two suggestions; first, identify different ways to support families through things like improved materials, “what to do while waiting” or facilitate family and provider meet and greets. The second is to improve partnerships and outreach with people or organizations that families would typically be connected to, e.g., WIC, school nurses, local agencies, and Family Voices groups. The professional group discussed outreach and connection to rare disorder groups or Federally Qualified Health Centers and increased education or professional development on unique topics.

Respondents were asked about satisfaction levels with NERGN communication and relationship building among partners. Of those that answered, a majority (n=22) indicated that they were satisfied or very satisfied while a couple (n=2) indicated they were dissatisfied (see Fig. 2).



Stakeholders were asked for their recommendations to improve upon communication and relationship building. A small number responded (n=8), however, they suggested an increase in communication and collaboration among partners regarding NERGN’s services, additional education opportunities, and support by collaborating with genetic counselors and primary care providers.

NERGN’s Role: Future Work



When asked about how NERGN can support their community in accessing genetic services, many respondents indicated multiple areas of opportunity (see Fig. 3). The most frequent responses included increased access to web-based information, connecting partners for best practices/ knowledge sharing, and highlighting access to social supports.

Stakeholders were asked to comment on what additional supports NERGN could provide to their community. Themes respondents addressed were in education and training, collaboration, and increased connection between stakeholders.

“A partnership approach of support to these families where you have PCP/Specialist/Advocacy Org would be powerful, efficient and effective. This is what families are asking for.”

The consumer/family member group was asked about what steps they take in accessing genetic services if there is a delay. They indicated that they do research, call providers frequently, talk to the office coordinators and use positive self-talk.

The professional group was asked what unmet needs they encounter within their community regarding access to genetic services. Answers largely focused on lack of providers, potential negative outcomes, insurance challenges, and lack of access to information. Additional thoughts included lack of knowledge within the primary care community, referrals, and wait time.

“For ABLE NH, the experiences shared by families impacted by disability revolve around feeling overwhelmed when providers of genetic services communicate a starkly negative set of outcomes which are frequently inaccurate descriptions of life outcomes.”

As a follow-up question, the professional group was asked about the challenges they see in their work that create delays in diagnosis or treatment and how NERGN can support communities to mitigate those delays. Commonly, access to services or lack of providers was associated with delays to care. Respondents suggested NERGN can support this through improving care coordination and relationship building among provider groups.

Additionally, it was asked of the professional group, whom in their community would benefit from NERGN’s support. Responses included medical professionals (OBGYN, doulas, paramedics, first responders, ER staff), students interested in genetic counseling, and refugees or new Americans.

As an end note, stakeholders were asked about whether they had additional comments for NERGN. Almost all responses were of praise or gratitude for NERGN’s work. One response indicated that NERGN could increase collaboration and reduce redundancy through communication.

“Looking forward to learning more about the great work NERGN is doing in NH.”

Institute on Disability/UCED



Steering Committee

Within the survey, respondents were able to identify whether they were on the Steering Committee. Members were asked a series of questions related to staffing, response, and goals. About half of members answered Strongly Agree that meetings were well-run and productive. All Steering Committee members that responded Agreed (n=2) or Strongly Agreed (n=5) that staff provides support to the Committee. Over half (n=4) of those who answered indicated that they Strongly Agree that NERGN responds effectively to questions and provides useful information. Steering Committee members Agree (n=5) or Strongly Agree (n=2) that they are providing guidance and support to NERGN in order to address its mission. When asked to comment, one member asked “Is there more some of us can be contributing with?”

Conclusions

Overall, responses to the Stakeholder Survey indicated that NERGN is taking the necessary steps to fulfill its goals and mission. In Year 2 (2018-2019), NERGN made progress in the areas of education, training, and collaboration with partners in order to reach underserved populations. Organizations or individuals who are more involved with NERGN’s activities are more inclined to agree that progress has been made. Many respondents indicated that NERGN has a responsibility to convene with other groups. While this is valid, it is unclear whether respondents fully understand NERGN’s role or scope of work, specifically as it relates to involvement with direct practice groups. The survey highlights continued work surrounding the NERGN brand. Specifically, creating additional visibility and growing public knowledge about what NERGN’s role is within the genetic services landscape, activities they participate in, and what resources they promote or create.

The low response rate further highlights the importance of visibility, partnerships, and collaboration which might lead the management team to consider whether the right groups are being targeted with information. Another factor which may have contributed to the response rate is that in Year 1 (2017-2018) stakeholders were not asked to complete a survey and perhaps stakeholders were less involved as a result. This thought might lend itself to improved or increased communication among stakeholders; harkening back to the additional comments provided where it was suggested that NERGN “increase collaboration and reduce redundancy of communication.”