

Assessing the Strengths and Weaknesses of the REiNS Patient Representative Program

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Response Evaluation In Neurofibromatosis Schwannomatosis
INTERNATIONAL COLLABORATION

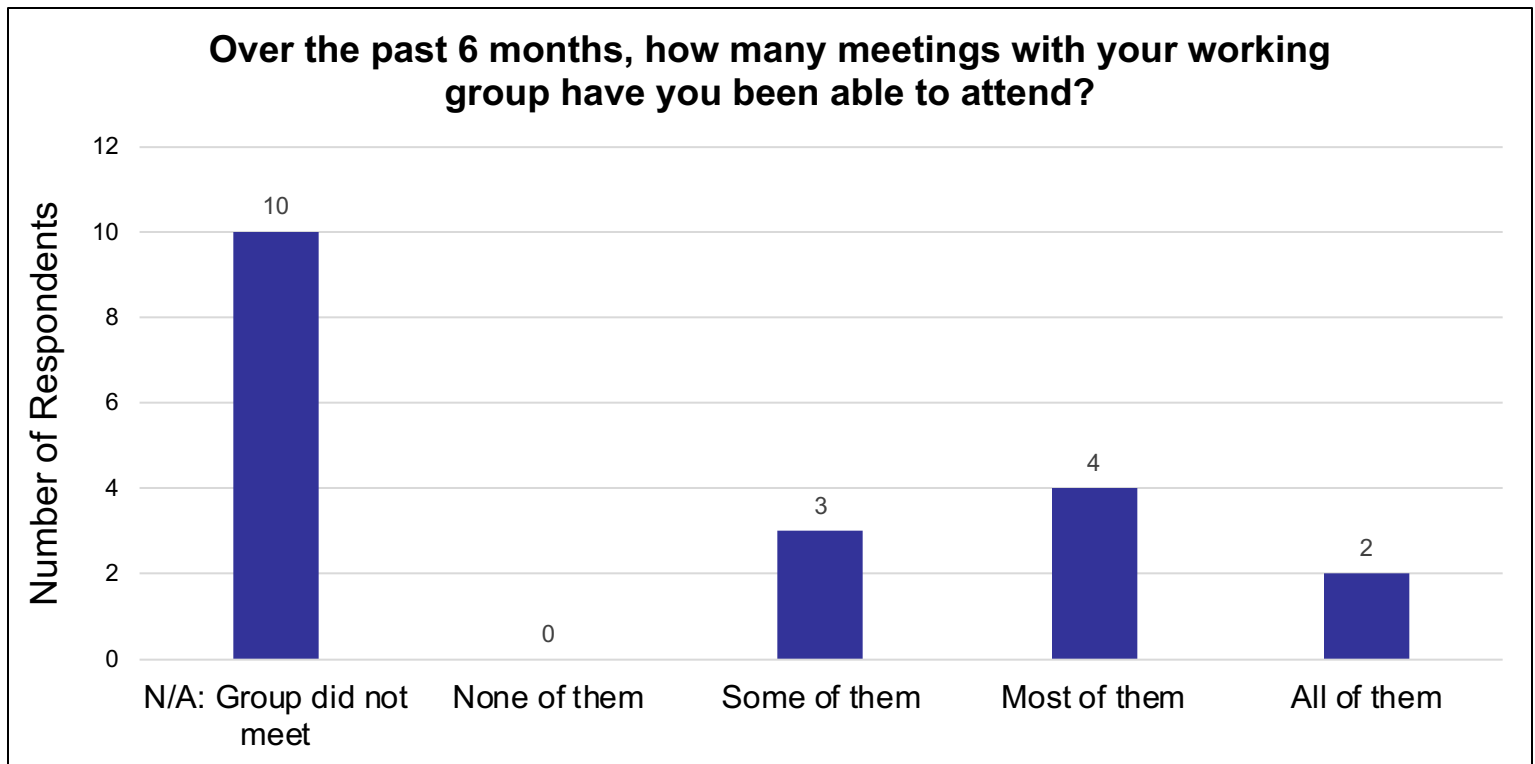
Our Journey

- Initial cohort of 30 patient representatives joined REiNS in Fall 2017
- Patient representation working group formed
- Informal survey of patient representatives in April 2019



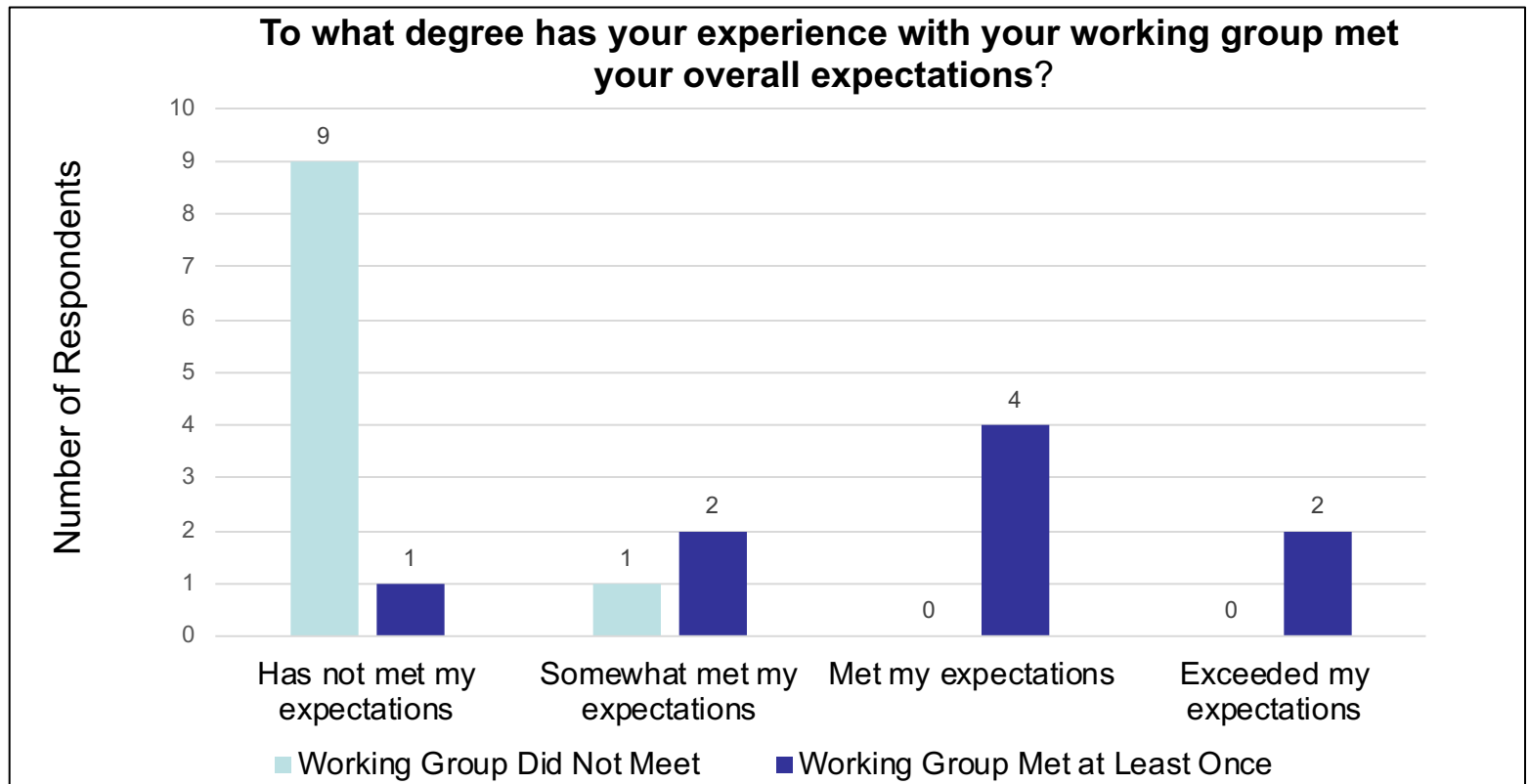
Meeting Frequency and Attendance

- 19/28 patient representatives responded (68% response rate)
- 10 PRs reported no working group meetings in the past 6 months
- Even in groups that met, most respondents were not able to attend all meetings



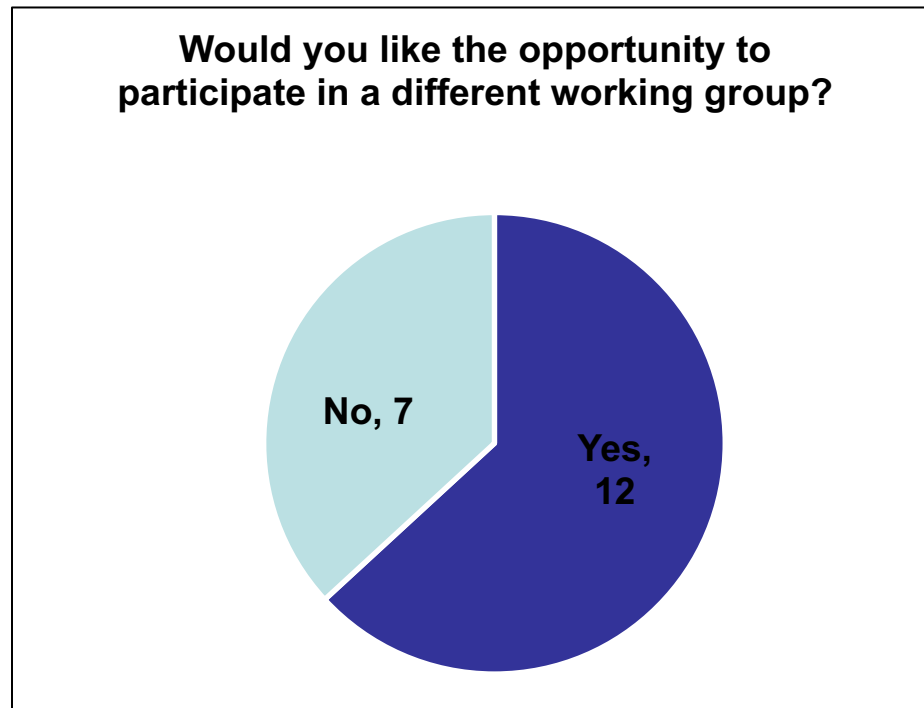
Patient Representative Satisfaction

- 10/19 (53%) of respondents felt their experience had not met their expectations
- For patient representative in working groups that had met over the past 6 months, 6/9 (66%) of respondents said the experience met or exceeded their expectations



Interest in Moving Working Groups

- 64% of respondents indicated that they would like the opportunity to participate in a different working group



Addressing Patient Representative Concerns

1. Formed patient engagement evaluation subcommittee
2. Volunteers assessed:
 - Do current representatives want to end their term as a patient representative or continue their role?
 - If staying in REiNS, do representatives want to switch working groups and/or serve on multiple working groups?
3. Launched larger scale, formal survey of all REiNS members to further understand strengths and weaknesses of REiNS patient representative program



Thank you to our departing
patient representatives!



Current REiNS Patient Representatives

- 2-4 patient representatives per working group
- If you did not receive an email on Friday with your working group information, please contact Vanessa.Merker@va.gov



Patient Engagement Evaluation Subgroup

Maureen Hussey

Andrea Gross

Andrés Lessing

Bev Oberlander

Vanessa Merker

Mikki Montgomery

Renie Moss

Scott Plotkin

Traceann Rose

Raquel Thalheimer

Tracy Wirtanen

Pam Wolters



Evaluation Survey Launched at September REiNS Meeting



Resize font:



REiNS Patient Engagement Survey

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Study Title: Evaluating and Improving Patient Engagement in the Response Endpoints in Neurofibromatosis and Schwannomatosis (REiNS) Collaboration

Principal Investigator: Scott Plotkin, MD, PhD

Thank you for your interest in this brief, anonymous survey about patient engagement in REiNS.

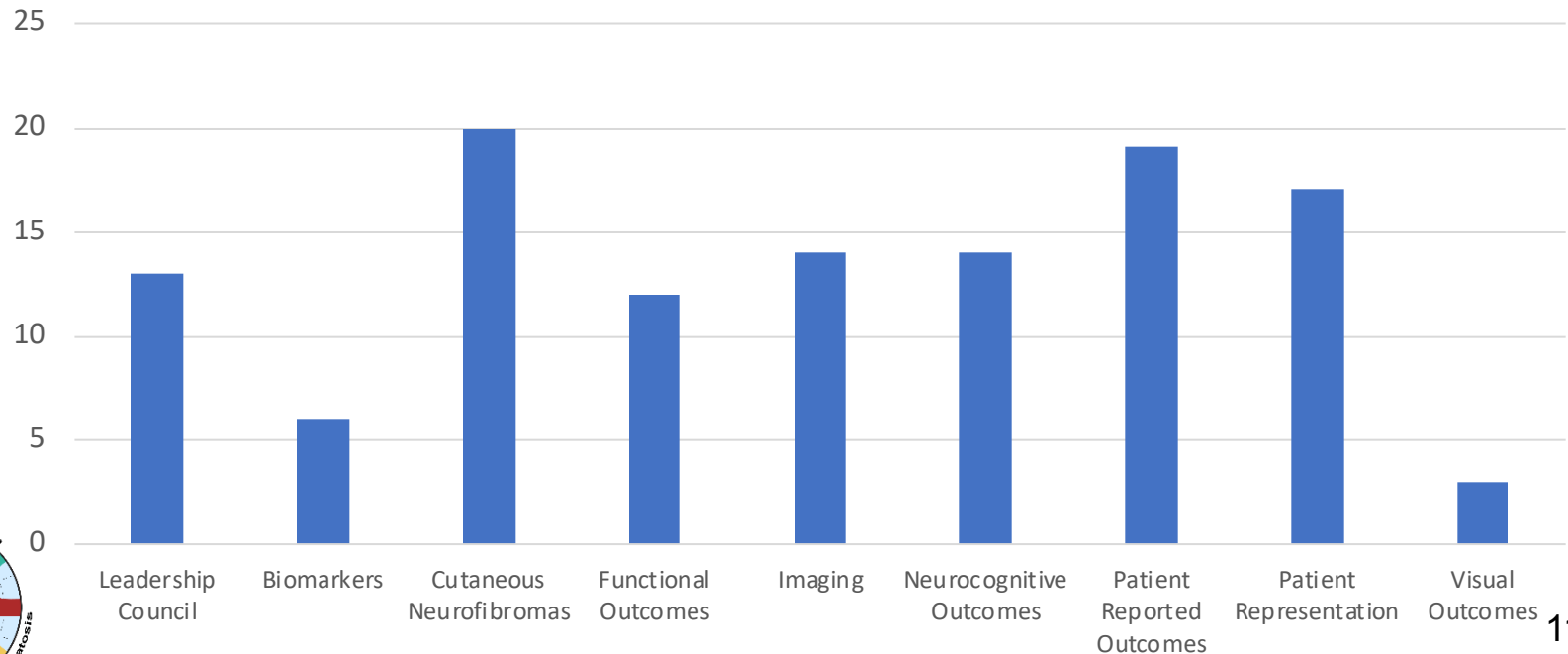
This is a research study designed to collect feedback from all REiNS members about the REiNS patient representative program. We obtained your name and email address from the REiNS membership list and are asking you to participate because you currently or previously participated in a REiNS working group. We expect up to 150 REiNS members to participate in this survey.

[This survey has 8 questions and should take approximately 15-20 minutes to complete.](#) You may skip any questions you do not wish to answer. However, we hope you will complete as many questions as possible. The information you provide will help inform our strategy for improving REiNS patient engagement in the future.



Survey Responses

- 63/172 participants (37% response rate)
 - 18 patient representatives (60% response rate)
 - 40 clinicians and researchers
 - 5 members of patient advocacy organizations



Survey Topics

- For everyone:
 - Things that help and things that didn't
 - Contributions of patient representatives
 - Priorities for future
- For patient representatives only:
 - Reasons for joining REiNS
 - How experience fulfilled expectations (or not)
- For other REiNS members only:
 - Cost/benefit ratio of patient engagement



Freelisting

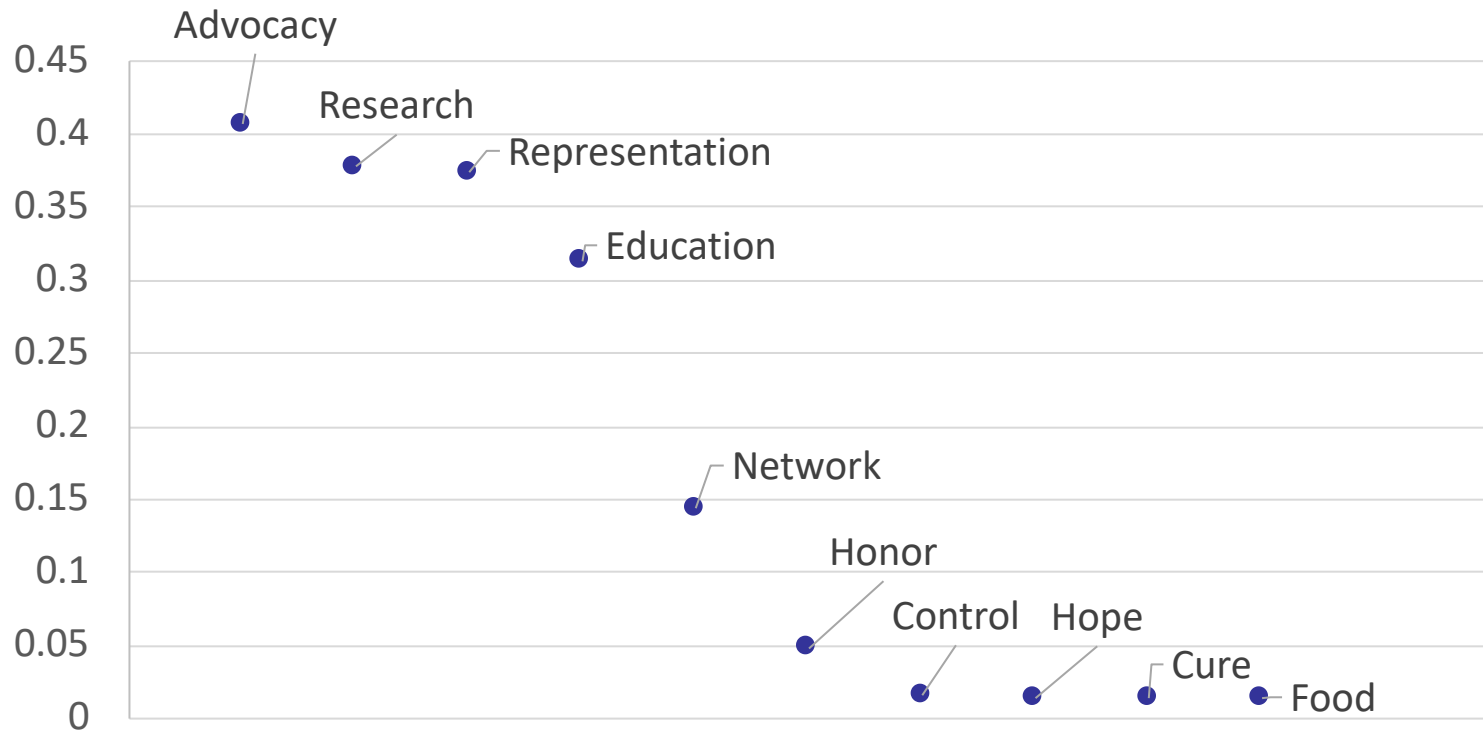


- Technique from cultural anthropology
- Ask people to list as many answers as possible to a question
- Analyze frequency and rank of each answer
- Helps us understand what answers are most salient and whether there is consensus among group members

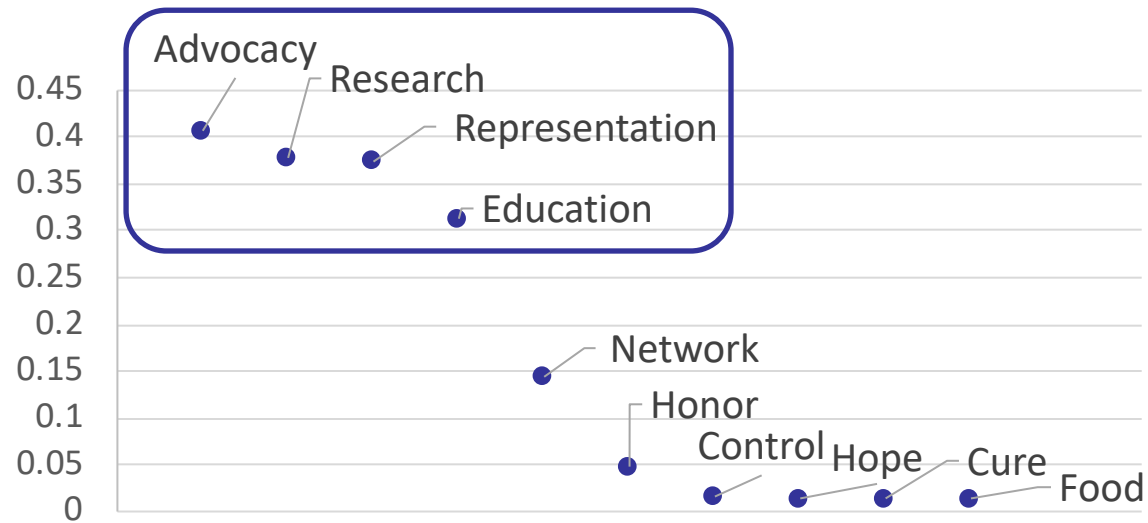
Example of Coding Process

| ID | Rank | Reasons Joined | Code |
|----|------|---|-----------|
| 39 | 1. | To contribute to the research process | Research |
| 39 | 2. | To understand where we stand with respect to finding treatments for NF related symptoms | Education |
| 39 | 3. | To meet the researchers leading NF research | Network |
| 39 | 4. | To find a cure for NF | Cure |

Reasons for Joining REiNS

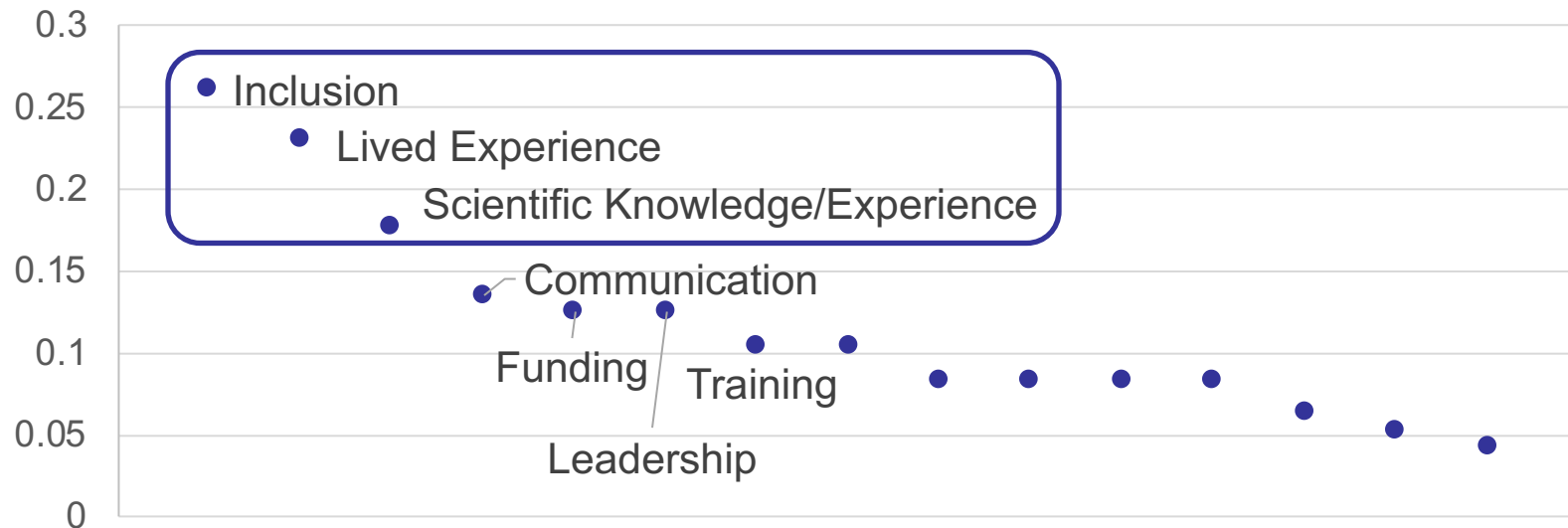


Reasons for Joining REiNS



Things that Have Helped

(*Patient Representatives Only)



“Positive/inclusive environment” & “genuine feeling of openness from clinicians/scientists”

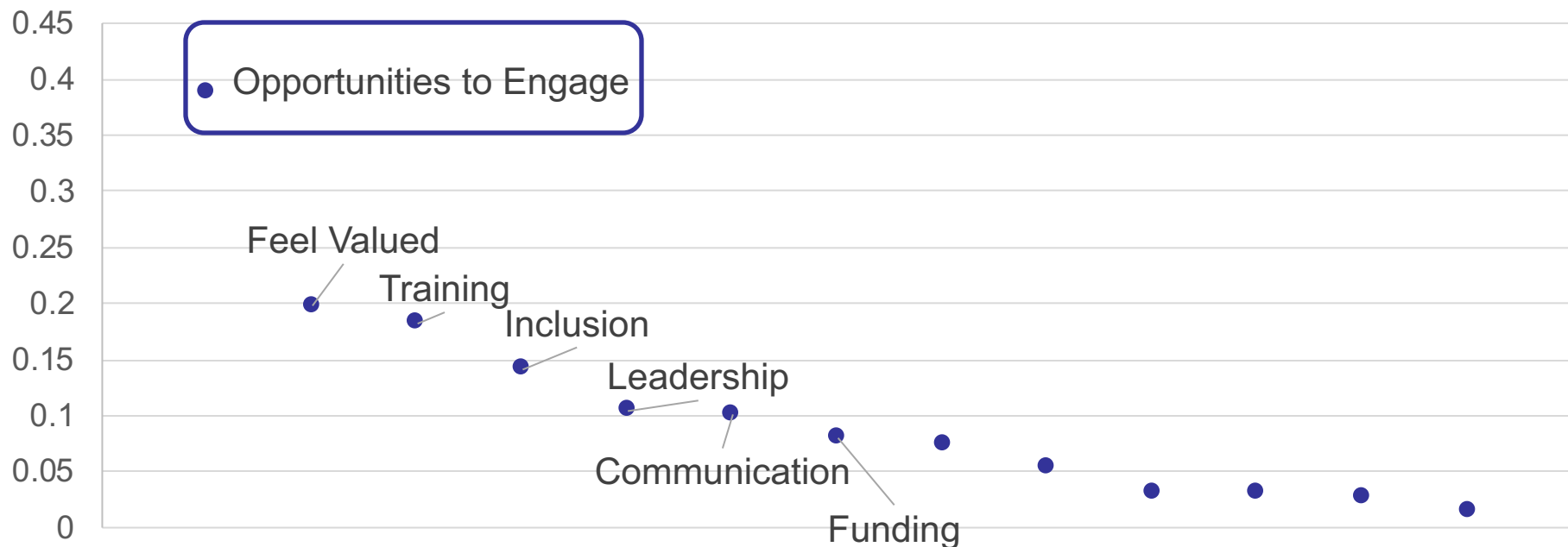


“Having real world experience with issues associated to NF” & “years of talking with other NF patients and families and gathering their input as to what is important to them”

“My existing ability to read scientific papers” & “prior experience working with scientists/clinicians”

Things that Have Helped

(*Other REiNS Members Only)



“Access to the monthly call in meetings”, “in-person meeting participation”, & “give them specific tasks to do for the working group”

“Asking them questions and for input on the calls” & “making patients representatives feel valued”

“Provide training for being a patient representative in general and in the specific working group”

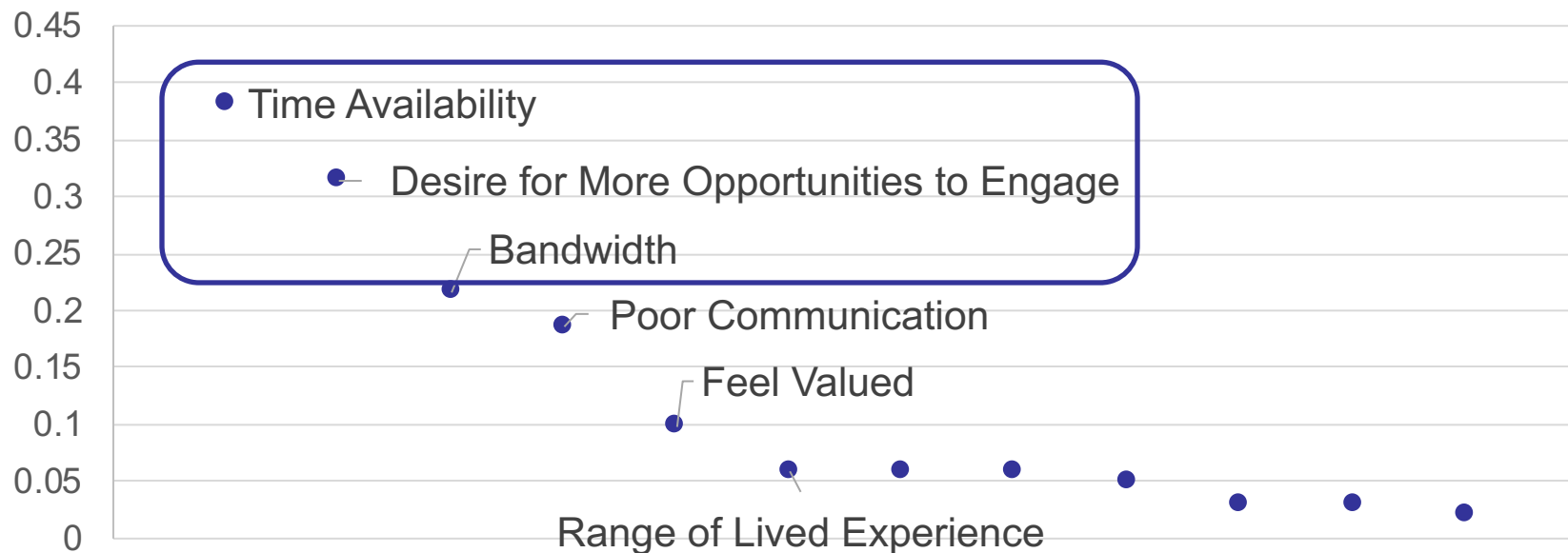
Things That Have Helped Patient Representatives

| Patient Representatives | | Other Members |
|-------------------------|---------------------------------|---------------|
| 1 | Inclusion | 4 |
| 2 | Lived Experience | 11 |
| 3 | Scientific Knowledge/Experience | 12 |
| 8 | Opportunities to Engage | 1 |
| 9 | Feel Valued | 2 |
| 7 | Training | 3 |



Challenges and Barriers

(*Patient Representatives Only)



“Phone calls that are during the day and hard for me to schedule around”, “evening meeting times” & “time zone differences”

“Lack of working group activity” & “Patient Reps who are willing should go through IRB to be able to fully contribute”

“Bandwidth as working parent” and “previous volunteer commitments to the NF community”

Challenges and Barriers

(*Other REiNS Members Only)



“Sometimes the discussions get very technical which make it difficult for patient reps to participate” & “understanding of scientific information when discussing research”

“Scheduling challenges”, “time zones” & “sometimes not giving enough advanced notice of meetings”

“Making the patient rep feel that their perception/knowledge/contribution was just as important as those of the professionals.”

Challenges and Barriers for Patient Representatives

| Patient Representatives | | Other Members |
|-------------------------|---|---------------|
| 1 | Time Availability | 2 |
| 2 | Desire for More Opportunities to Engage | 14 |
| 3 | Bandwidth | 7 |
| 4 | Poor Communication | 5 |
| 7 | Scientific Knowledge/Experience | 1 |



Comparing Facilitators and Barriers

| | Patient Reps | Other Members |
|---|-------------------------|--------------------------|
| Prior Scientific Knowledge/Experience Helped Patient Reps | 3rd | 12th |
| Lack of Scientific Knowledge and/or Technical Discussions are a Barrier | 7th | 1st |
| | Patient Reps | Other Members |
| Having Opportunities to Engage Has Helped | 8th | 1st |
| Patient Reps Desire More Opportunities to Engage | 2nd | 14th |

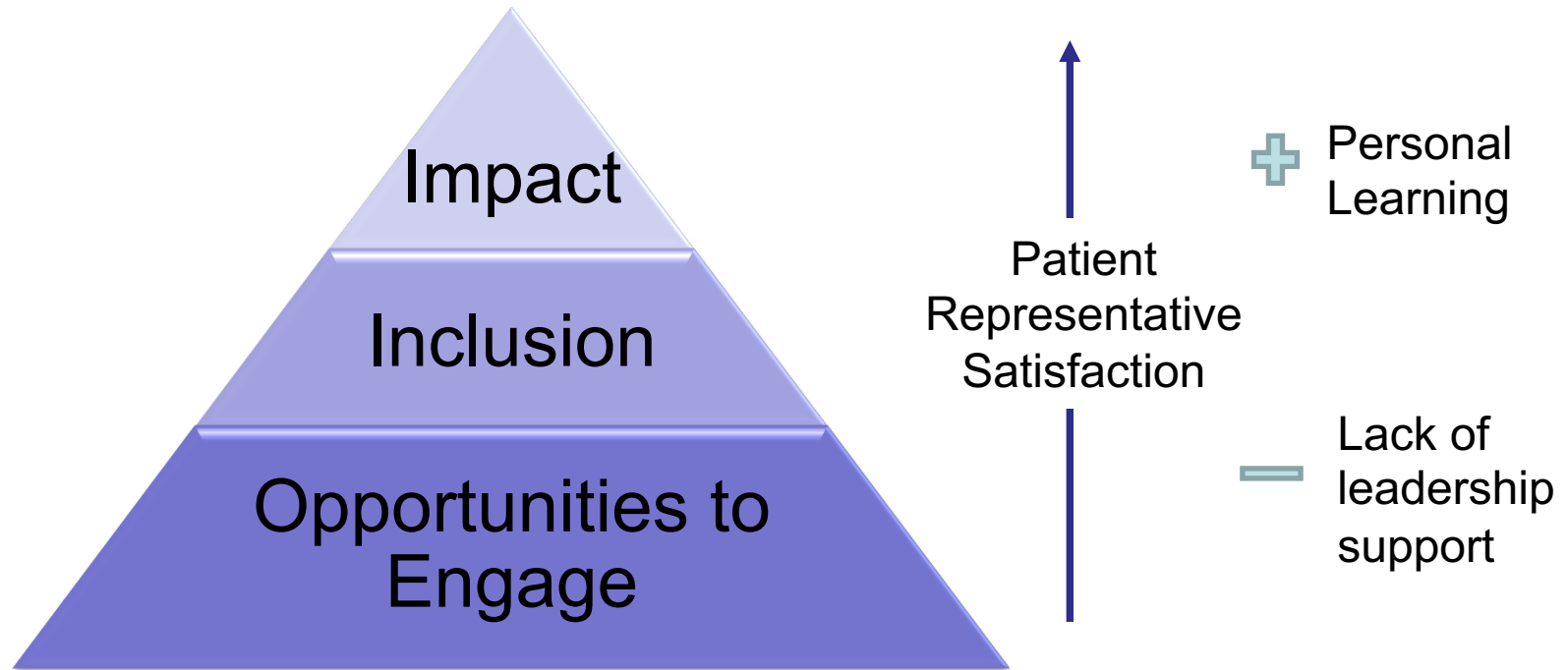


Content Analysis

- Common qualitative analysis technique
- Categorize and synthesize responses to open-ended questions
- Deductive (top-down) or inductive (bottom up)

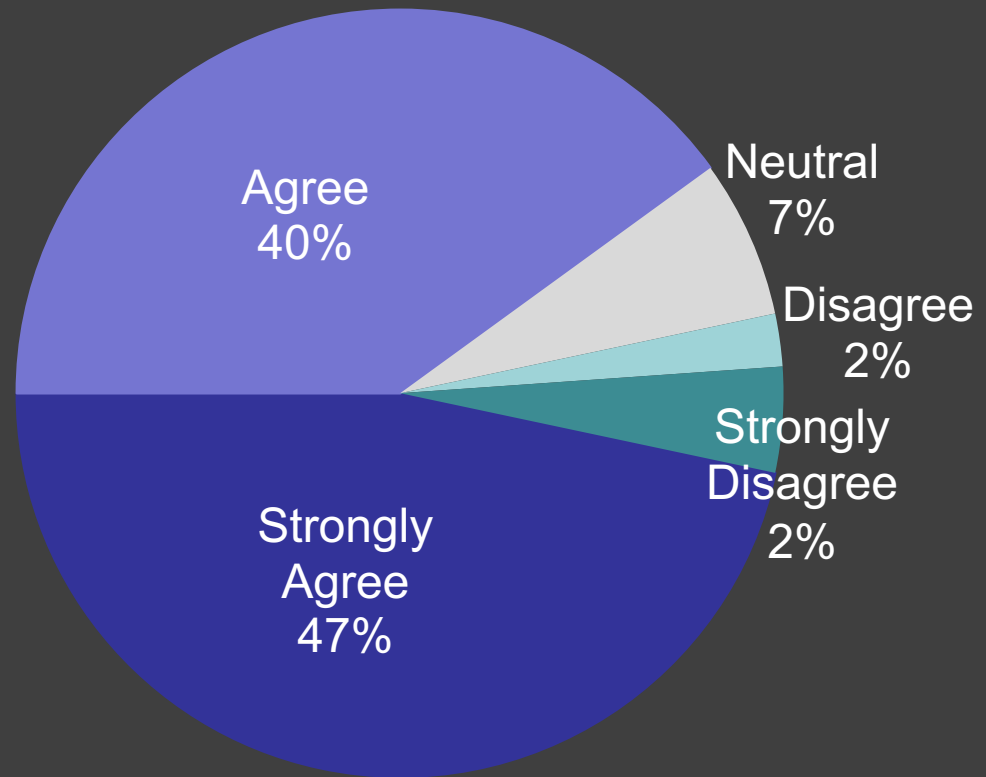
In what ways has your experience in REiNS fulfilled (or not fulfilled) your expectations for being a patient representative?

- Variability in working group experiences



- Consequences for unfulfilled expectations:
Disappointment → reduced participation → drop-out

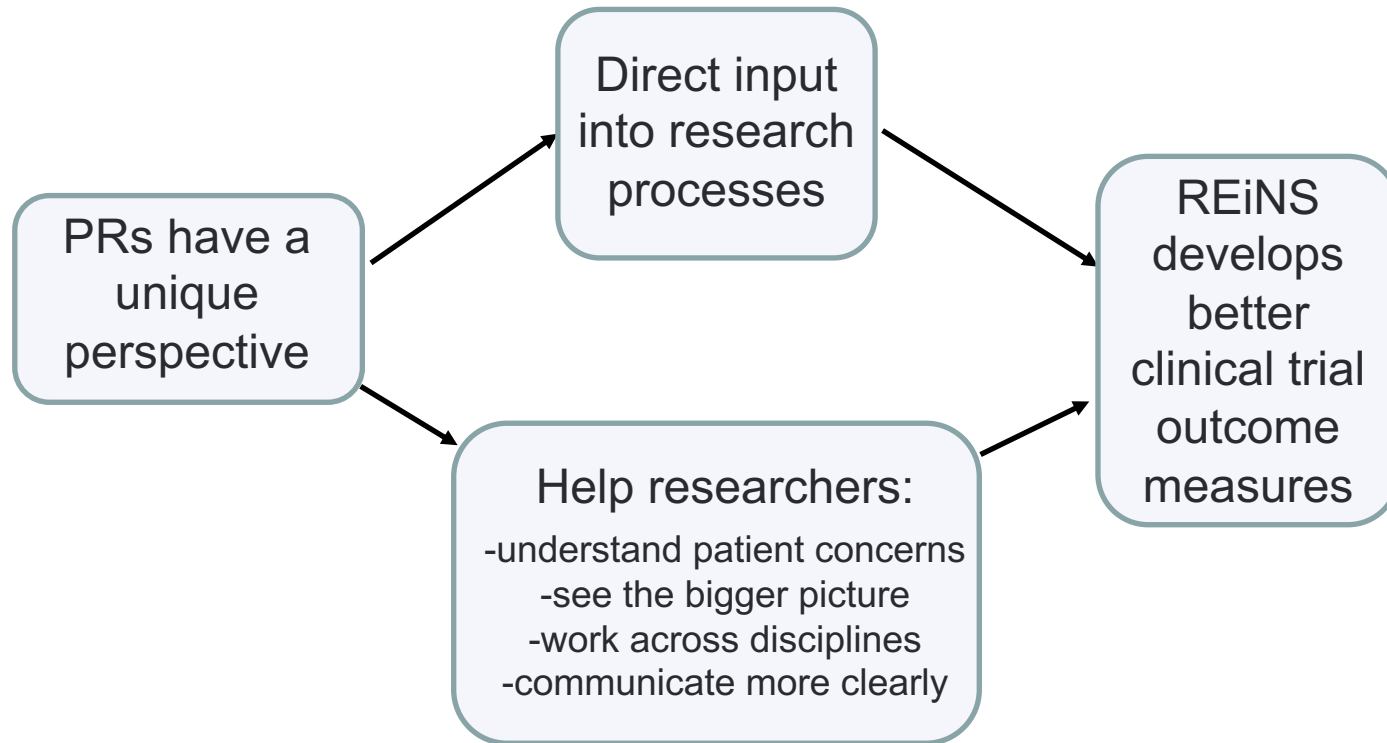
The benefits of having patient representatives in REiNS outweigh the effort/cost.



Engaging patient representatives is critical, but it does take work and may have some limitations in scope.

- Critical
- Necessary
- Vital
- Invaluable
- Fundamental
- Essential
- Crucial
- Cannot Imagine Doing This Without Them





Caveats:

- It takes time and resources to make this process work.
- PRs may not be able to help in more technical research tasks and/or may need education to assist in research tasks.
- Some respondents feel we have a moral obligation to include patients irrespective of any direct benefits to REiNS.



Patient Representative Contributions

EXHIBIT 2

Summary of contributions of engagement and effects of contributions described in included studies

| Project phase | Themes for contributions of engagement |
|----------------------|--|
| DESIGN | |
| Research focus (41) | Identification or expansion of topic (5) or aims or research questions (5) Determination of outcomes (35) Choice of comparator(s) (6) |
| Research design (19) | Practical aspects (for example, setting or timeline) (7) Broader inclusion/less restrictive exclusion criteria (7) Choice of designs, including numbers/types of arms (9) and participant allocation/randomization (3) |
| Interventions (54) | Adaptation of intervention elements, including delivery (20), materials or tools (14), and topics or content (18) Training for intervention providers (4) |

Range of Contributions and Impact

- Research focus, research design, recruitment, data collection, data analysis, and dissemination
- Clinical trial measures that:
 - Address patient concerns (= more relevant)
 - Are more feasible to implement
 - Are less burdensome for patients to complete
 - Are easier for patients to understand (= more accurate)
 - Provide meaningful results to patients and clinicians



Priorities Moving Forward

- More patient representative involvement
 - Give current PRs more opportunities to be involved
 - Including expanded input/roles and by working across groups
 - Recruit more PRs
- Increase diversity of patient representatives
- Help patient representatives make a difference and feel valued
- Develop ongoing patient representative feedback/evaluation mechanism



Next Steps

- Subgroup analyses
- Integrating analysis across questions
- Publish manuscript in Neurology supplement
- Evaluation subgroup to discuss findings and present recommendations to Leadership Council



Breakout Session

- Split into small groups
- Every group should nominate at least 1 note-taker and 1 presenter
- 10 minutes each
 - Brainstorm ideas
 - Debate pros/cons of top choices
 - REiNS policy recommendations and next steps
- Reconvene at 2:45 to present and discuss

