

Response Evaluation In Neurofibromatosis Schwannomatosis  
INTERNATIONAL COLLABORATION

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# Evaluating the REINS Patient Representative Program

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September 22, 2019



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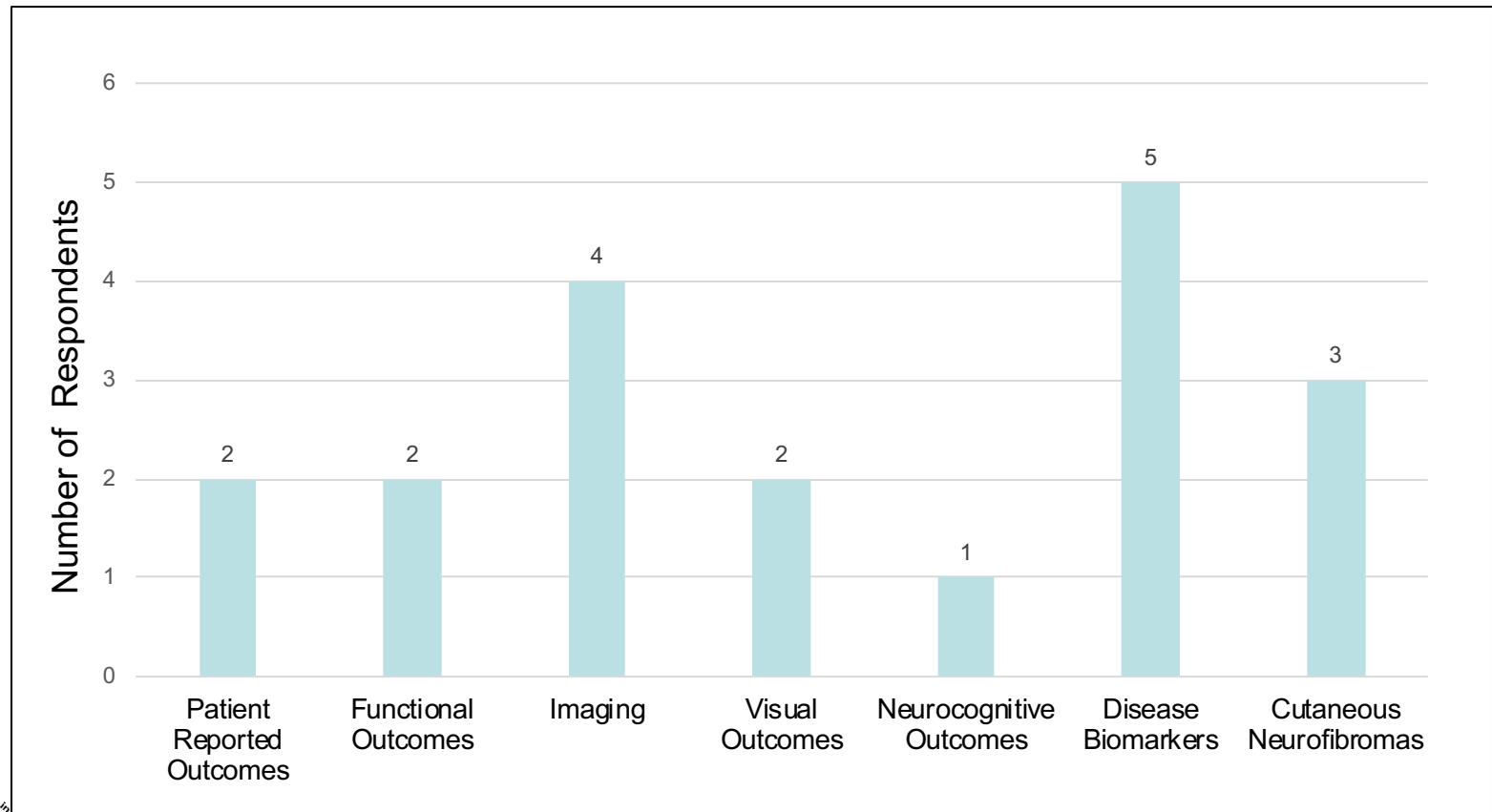
# Patient Engagement Evaluation Subgroup

- Maureen Hussey
- Andrea Gross
- Andres Lessing
- Bev Oberlander
- Vanessa Merker
- Mikki Montgomery
- Renie Moss
- Scott Plotkin
- Traceann Rose
- Raquel Thalheimer
- Tracy Wirtanen
- Pam Wolters



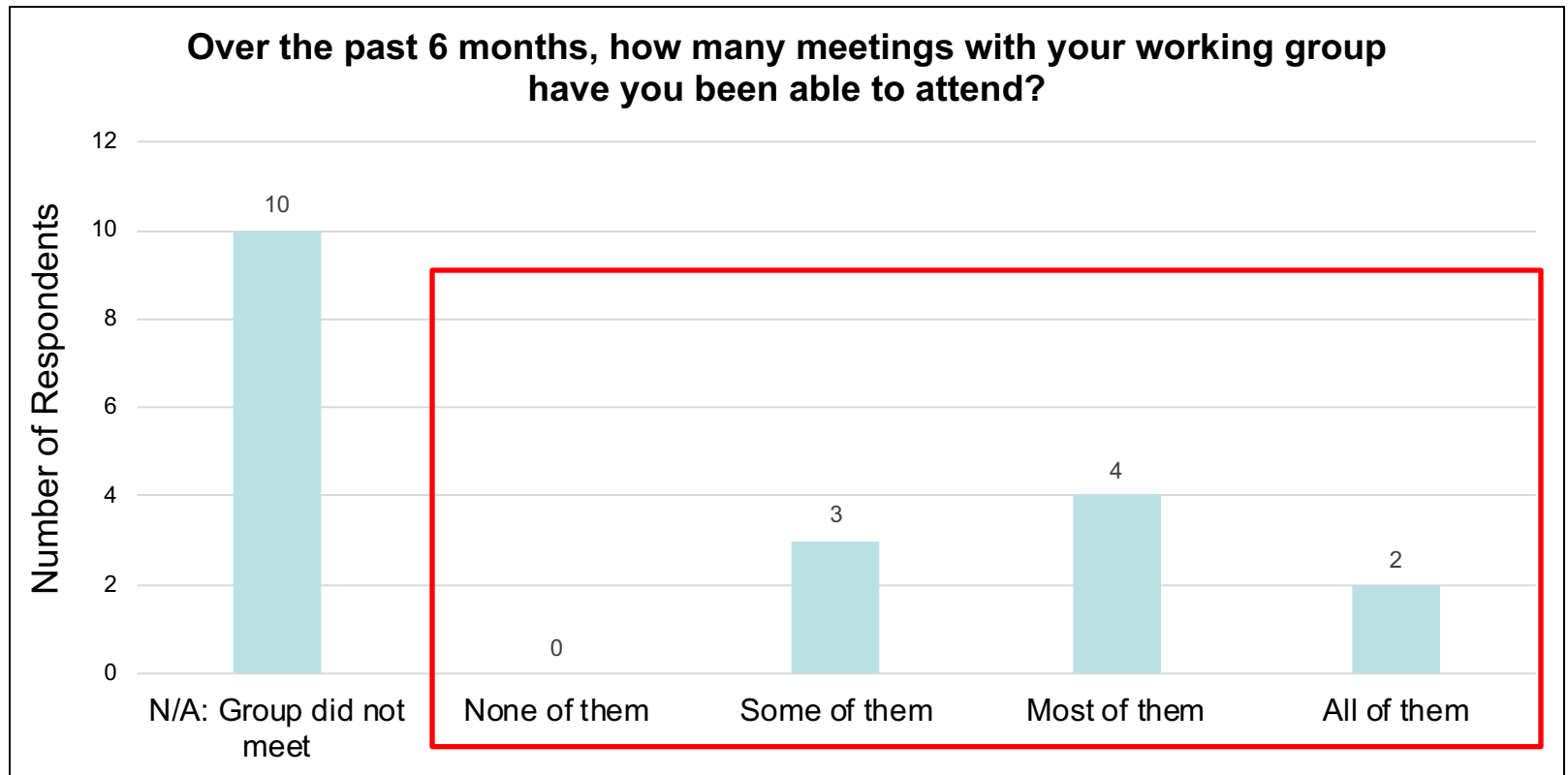
# Respondent Summary

- 19/28 patient representatives (68% response rate)



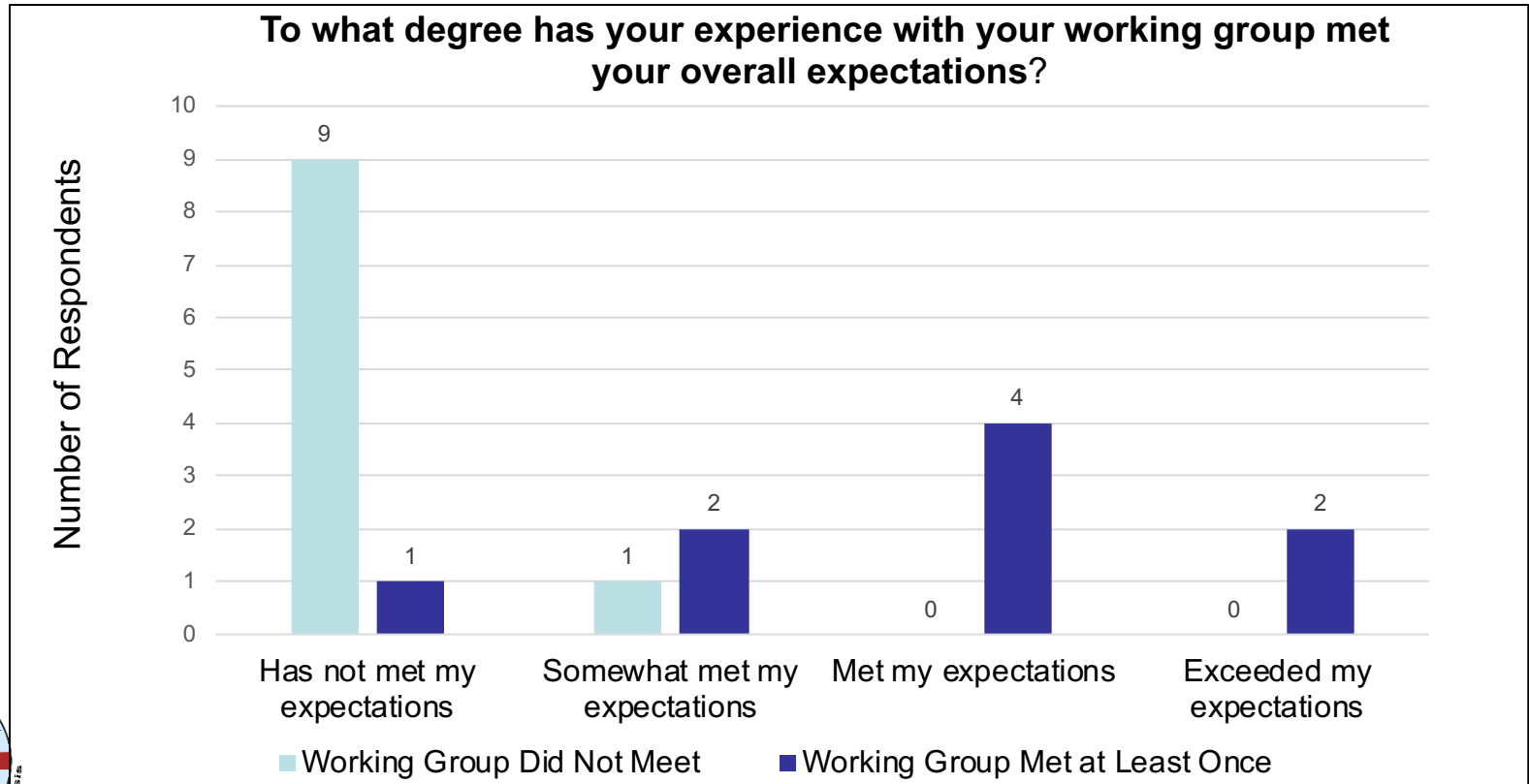
# Meeting Frequency and Attendance

- 10 patient representatives (53% of survey respondents, 36% of all patient representatives) reported their group did not meet in the past 6 months
- Even in groups that met, most respondents were not able to attend all meetings



# Patient Representative Satisfaction

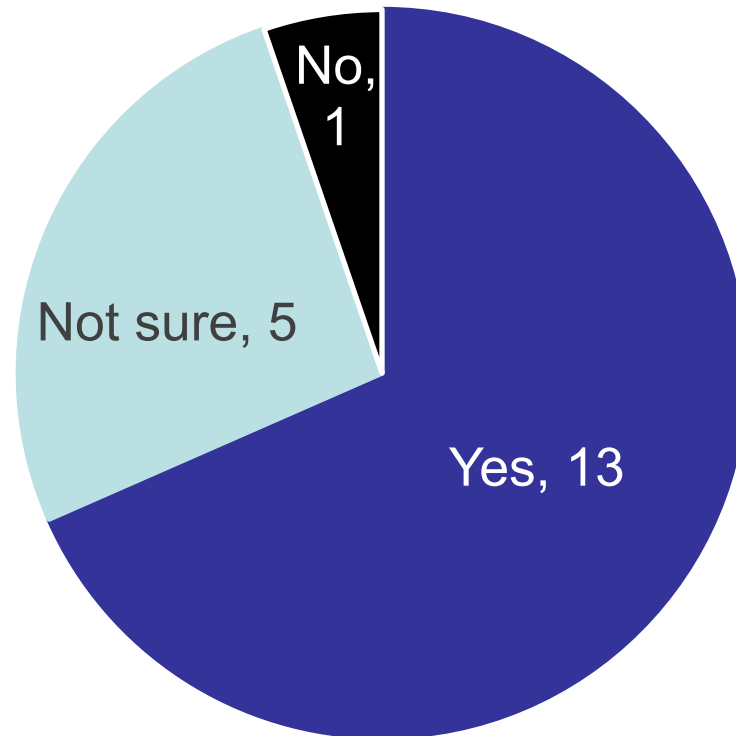
- 10/19 (53%) of respondents felt that their experience had not met their expectations
- For patient representative in working groups that have met over the past 6 months, 6/9 (66%) of respondents said the experience met or exceeded their expectations



# Interest in Current Working Groups

- Only 1 respondent would definitely not want to continue in their current working group

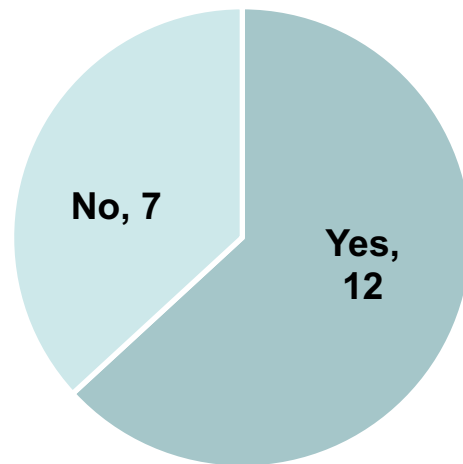
Would you like to continue with your current working group?



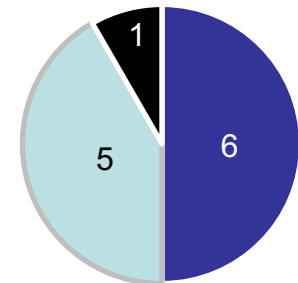
# Addressing Patient Representative Concerns

- 12/19 (64%) of respondents indicated that they would like the opportunity to participate in a different working group
  - 6 did not want to continue or were unsure about continuing on their current working group (i.e. potentially want to change working groups)
  - 6 wanted to continue in primary working group (i.e. potentially want to serve on multiple working groups)

Would you like the opportunity to participate in a different working group?



Primary Working Group



- Continue
- Unsure
- Do Not Continue





# Addressing Patient Representative Concerns

- Implement plan to allow patient reps to switch groups or serve on multiple groups
- Re-assess participation across working groups; identify those who don't want to continue
- Potentially recruit new patient representatives to fill gaps



# Ongoing Initiatives

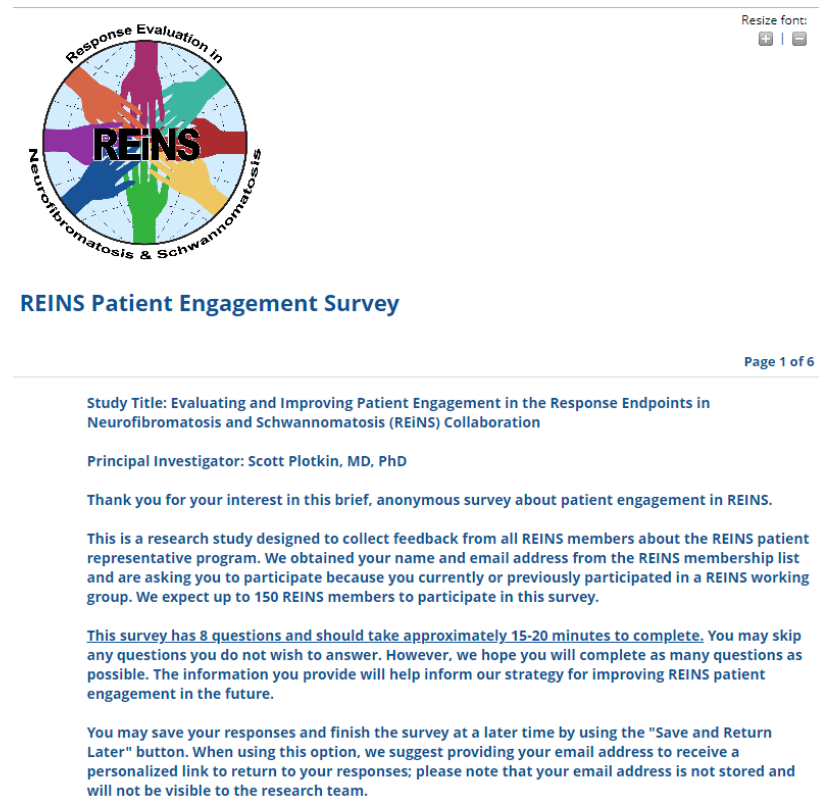
- Created and launched patient engagement survey for all REINS members

Check your email now!

Only 8 questions.

Available at <https://is.gd/>

[REINSPatientEngagement](https://is.gd/REINSPatientEngagement)



The screenshot shows the first page of a survey. At the top left is the REINS logo. To the right of the logo is the text 'REINS Patient Engagement Survey'. Below this is the page number 'Page 1 of 6'. The main content area contains the following text:

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.

You may save your responses and finish the survey at a later time by using the "Save and Return Later" button. When using this option, we suggest providing your email address to receive a personalized link to return to your responses; please note that your email address is not stored and will not be visible to the research team.