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GRAPPA Patient Research Partner Network Composition and Engagement: A Survey to Determine Strategic Areas for Growth

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ABSTRACT. The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) Patient Research Partner (PRP) Network conducted a survey to identify its key strengths and gaps, with the goal of enhancing its global reach and representation. The survey revealed strong gender parity and high long-term project participation among PRP members. However, it also indicated a need for greater ethnic and geographical diversity among the members. To address this, the PRP Network will expand its membership and specifically recruit partners from underrepresented regions such as Africa, Asia, Australia/New Zealand, South America, and Eastern Europe. Additionally, the network aims to expand its age range to include a more representative selection of research partners, thereby advancing GRAPPA's overarching objectives. The results of the survey were presented at the GRAPPA 2024 annual meeting.

Key Indexing Terms: GRAPPA, patient participation, psoriasis, psoriatic arthritis, researcher–patient relations

Introduction

The Group for Psoriasis and Psoriatic Arthritis Research (GRAPPA) invited 7 patients to the Patient Research Partner (PRP) Network in 2013.[1] The PRP Network has been instrumental in assisting GRAPPA with achieving its goal of including patient perspectives across priority areas such as treatment guidelines, outcome measure recommendations, and key research studies.[2-7] PRP members have experienced increased demands as the PRP Network has evolved to become more engaged in GRAPPA projects.[8] Given the increased demand, the network began working toward adding members to advance GRAPPA's mission. In 2019, 2 new members joined to bring current membership to 12 PRPs (11 active members).[4] To meet the goal of further expansion, the PRP Network designed a survey to understand the demographics and diversity of PRP Network members, identify gaps in PRP Network composition, and develop a membership recruitment strategy.

Methods

The survey aimed to collect detailed information on the GRAPPA PRP group, including age, race and ethnicity, gender, geographic location, educational background, and the group's experiences with their own psoriasis (PsO) and psoriatic arthritis (PsA). Additionally, it sought to understand perspectives that each PRP member provided and the roles of PRPs within GRAPPA.

The questionnaire was crafted using the Qualtrics survey tool and distributed online to all 12 GRAPPA PRP Network members. It was open for responses from December 19, 2023, to February 3, 2024, and received complete responses from 11 members. Participants had the option to skip any questions they preferred not to answer. The survey comprised 3 main sections: section A ("about you"), with 14 questions; section B ("about us"), with 9 questions; and section C ("final thoughts"), which included an open text box for additional comments. All responses were self-reported, but participants may have referred to their medical records when answering questions about the timing of onset and severity of their psoriatic disease (PsD). Given the small sample size and potential for participant identification from survey responses, responses were aggregated by a designated member of the PRP recruitment team.

Results

Section A: About you. Demographic characteristics of the 11 PRPs who completed the survey are shown in Table 1. Although the PRP Network currently maintains an equal gender split, the majority of members are over the age of 55, White, and highly educated, with over 90% of members holding a master's or doctorate degree. Network members who are not retired hold a variety of positions in medicine, pharmacy, public health research, academia, medical research, patient relations and empowerment, law, project management, and youth work. All but one of the survey respondents live in urban or suburban settings, and most members reside in North America and Northern Europe, except 1 member each from Brazil, Israel, and China.

Over 80% of the members surveyed have more than 7 years of experience as a PRP and over 80% are involved as PRPs in other organizations and projects outside of GRAPPA. As the Network shares collective PsD perspectives from both rheumatology and dermatology, we wished to understand the members' disease course, burden, and severity in more detail. Table 2 gives information regarding time of diagnosis with PsO or PsA vs first

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Table 1. Current PRP Network member characteristics.

	Total Respondents, N = 11
Age group, yrs	
25-34	1 (9)
45-54	2 (18)
55-64	5 (45)
65-74	2 (18)
≥ 75	1 (9)
Gender	
Male	5 (45)
Female	6 (55)
Race and ethnicity[a]	
Chinese	1 (9)
Mixed-race Latine	1 (9)
South Asian or Asian Indian	1 (9)
White	8 (73)
Education	
Bachelor's degree	1 (9)
Master's degree	4 (36)
Doctorate degree	6 (55)
Country of residence	
USA	4 (37)
Canada	1 (9)
Brazil	1 (9)
Norway	1 (9)
China	1 (9)
Netherlands	2 (18)
Israel	1 (9)
Residential locale	
Urban	6 (55)
Suburban	4 (36)
Rural	1 (9)

Values are n (%). [a] Self-identified.

Table 2. Disease background of survey respondents.

	Total Respondents, N = 11
Worst level of PsO ever experienced, % BSA	
< 3, mild	5 (45)
3-8, moderate	4 (36)
> 10, severe	2 (18)
Age at which first onset of PsO symptoms was noticed, yrs	
13-17	3 (27)
18-24	2 (18)
25-34	2 (18)
35-44	2 (18)
No response	2 (18)
Age at which PsO was diagnosed, yrs	
13-17	3 (27)
18-24	1 (9)
25-34	2 (18)
35-44	3 (27)
No response	2 (18)
Age at which first onset of PsA symptoms was noticed, yrs	
13-17	2 (18)
18-24	2 (18)
25-34	2 (18)
35-44	3 (28)
No response	2 (18)
Age at which PsA was diagnosed, yrs	
13-17	1 (9)
18-24	1 (9)
25-34	2 (18)
35-44	5 (46)
No response	2 (18)

Values are n (%). BSA: body surface area; PsA: psoriatic arthritis; PsO: psoriasis.

symptoms, demonstrating that several PRP Network members have experienced mild to severe PsO from a younger age (ie, 25-35 years). Not unexpectedly, there is a gap in time from first experiencing symptoms to diagnosis. Given the current age ranges of the members and age at diagnosis, one can infer there is significant lived experience with both PsO and PsA.

Section B: About us. This section explored member perspectives on the composition of the PRP team and what elements should be maintained or expanded upon when recruiting new members (Figure). There was significant agreement among members that the network needed more diversity and should prioritize recruiting members from countries not currently represented in the network, as well as individuals from diverse racial and ethnic backgrounds. Members also agreed the network needs younger members. Respondents stated the network leaders needed to engage more PRP members in GRAPPA working groups and projects, and encourage more partnerships with the physician members. This section also explored the maximal number of monthly hours members felt they should devote to GRAPPA activities. Three participants each stated 6, 8, or 12 hours, 1 stated 10 hours, and 1 stated more than 14 hours per month.

Section C: Final thoughts. One key insight from the open-ended survey responses was the need for PRP leadership to initiate timely dissemination of information and calls for participation in projects that will be initiated involving PRP members. Project information should be disseminated ahead of the project, including a lay description, a summary of expected time commitments, and other relevant details. Delays in dissemination of this information posed a significant barrier to PRP participation.

Discussion

The results of the survey helped provide a roadmap for recruitment of new PRPs by identifying existing gaps in membership. To align with GRAPPA's diverse global membership, the network must enhance its diversity with respect to geographic location, race and ethnicity, and age. As the PRP Network expands its membership, care must be taken to avoid tokenism.[9,10] PRP Network infrastructure must be adapted to give members without medical backgrounds or English proficiency a voice in the organization.

Additionally, balancing the time required for volunteering against the age of members is crucial, as younger members

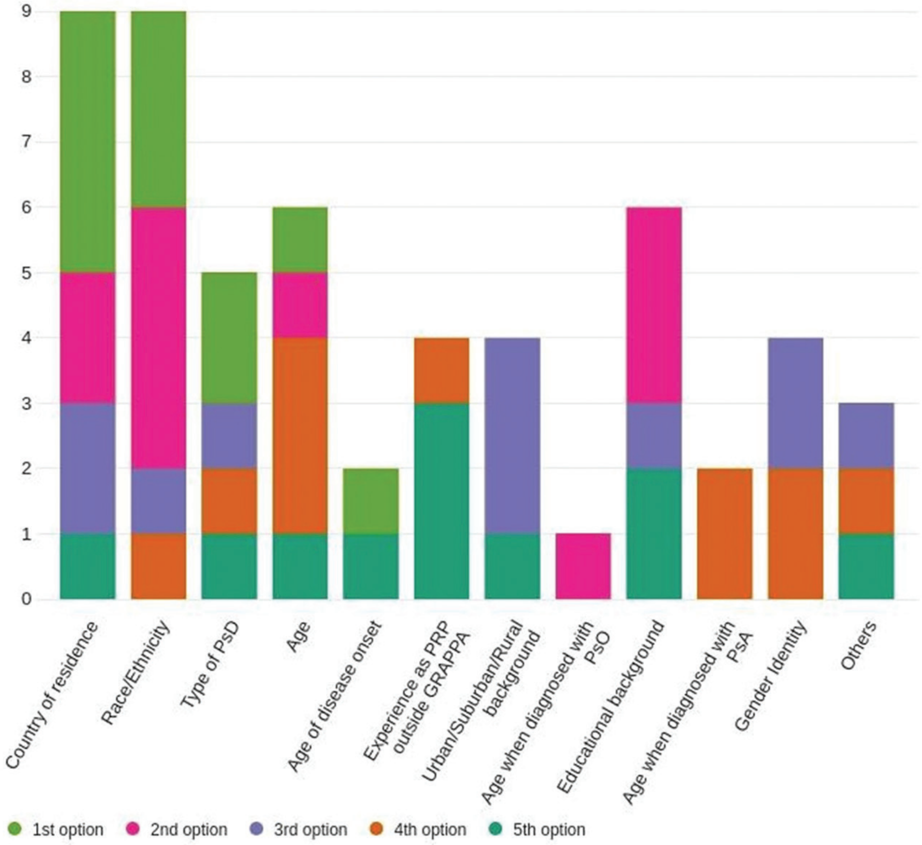

Figure. Survey results regarding criteria to prioritize when recruiting new members to the PRP Network, ranked accordingly (1st option, 2nd option, and so on). "Others" includes (1) the ability to converse and write well in English; (2) willingness and readiness to contribute; and (3) financial background (ie, greater diversity of income levels may assist in identifying more representative research questions for the Network; lower-income individuals will have more difficulty getting the care they need). Each of the "other" categories was endorsed by 1 PRP. GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; PRP: patient research partner; PsA: psoriatic arthritis; PsD: psoriatic disease; PsO: psoriasis.

may have more external commitments, such as employment or family. Network expansion should aim to reduce individual time commitments by distributing the workload among more members. A larger, more diverse PRP group will better accommodate the external commitments of members while still providing each member a platform to contribute to projects. To foster a diverse PRP group, providing need-based financial support and mentorship is vital.

Regarding race and ethnicity, lack of diversity in clinical trials has long demonstrated a critical need to broaden patient participation in clinical trials. Similarly, PRP perspectives should be made more diverse. Representation from Africa, Asia, Australia/New Zealand, South America, and Eastern Europe should be prioritized when recruiting new PRP members.

The current PRP network members reported a diverse range of experiences with PsD onset, burden, and severity, providing a well-rounded representation of the disease. However, not all types of PsD are represented among current PRPs.

In the current survey, participants from the network shared a preference for a maximum of 6 to 12 hours of dedicated GRAPPA PRP volunteer work per month. Although this is consistent with past informal queries on workload, this time commitment may be prohibitive to prospective members. Thus, the network must aim to spread projects among membership to ensure a greater balance. Further, the high percentage of PRPs engaged in other studies and projects outside of GRAPPA suggests the same individuals are repeatedly engaged, rather than incorporating new, diverse perspectives from other PRP Network members. This points to the need to expand the network to further PRP influence in research and clinical care. With support from the GRAPPA executive committee, the network will update its handbook and create a mentoring program to facilitate recruitment of new members.

In summary, we have a strong group of PRPs who are willing to volunteer and work on GRAPPA projects. To broaden our global reach and enhance diversity, the network needs to begin recruitment and onboarding new members before the GRAPPA 2025 annual meeting.

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COMPETING INTERESTS

CAL is a shareholder of Amgen and Arcutis Biotherapeutics. SMG is involved in this work as a private consultant or advisor and not in her capacity as a Johns Hopkins University faculty member. AK reports no conflicts of interest relevant to this article.

ETHICS AND PATIENT CONSENT

Institutional review board approval and patient consent were not required.

PEER REVIEW

As part of the supplement series GRAPPA 2024, this report was reviewed internally and approved by the Guest Editors for integrity, accuracy, and consistency with scientific and ethical standards.

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