RMD Open
Rheumatic & Musculoskeletal Diseases

SHORT REPORT

Evaluating the participation of junior members and patient and healthcare professionals representatives in EULAR task forces: results from an international survey

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To cite: Juge P-A, Kragstrup TW, Perez-Garcia LF, *et al*. Evaluating the participation of junior members and patient and healthcare professionals representatives in EULAR task forces: results from an international survey. *RMD Open* 2024;**10**:e004177. doi:10.1136/rmdopen-2024-004177

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/rmdopen-2024-004177).

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Received 1 February 2024
Accepted 23 April 2024

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ABSTRACT

Objective European Alliance of Associations for Rheumatology (EULAR) task forces (TF) requires participation of ≥2 junior members, a health professional in rheumatology (HPR) and two patient research partners for the development of recommendations or points to consider. In this study, participation of these junior and representative members was compared with the one of traditional TF members (convenor, methodologist, fellow and expert TF members).

Methods An online survey was developed and emailed to previous EULAR TF members. The survey comprised multiple-choice, open-ended and 0–100 rating scale (fully disagree to fully agree) questions.

Results In total, 77 responded, 48 (62%) women. In total, 46 (60%) had participated as a junior or representative TF member. Most junior/representative members reported they felt unprepared for their first TF (10/14, 71%). Compared with traditional members, junior/representative members expressed a significantly higher level of uncertainty about their roles within the TF (median score 23 (IQR 7.0–52.0) vs 7 (IQR 0.0–21.0)), and junior/representative members felt less engaged by the convenor (54% vs 71%). Primary factors that facilitated interaction within a TF were experience, expertise and preparation (54%), a supportive atmosphere (42%) and a clear role (12%).

Conclusion Juniors, patients and HPR experience various challenges when participating in a EULAR TF. These challenges differ from and are generally less pronounced than those experienced by traditional TF members. The convenor should introduce the participants to the tasks, emphasise the value of their contributions and how to prepare accordingly for the TF meeting.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ In addition to traditional members (ie, convenors, methodologists, experts and fellows), European Alliance of Associations for Rheumatology (EULAR) task force requires participation of at least three representative members—one health professional in rheumatology (HPR) and two patient research partners, and two junior members from the Emerging EULAR Network.

⇒ The participation of the junior or representative members in a task forces (TF) has never been evaluated.

WHAT THIS STUDY ADDS

⇒ Juniors, patients and HPR members faced specific barriers to active participation (uncertain role, inadequate preparation and difficulties for engaging) which differed from those experienced by traditional TF members.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Our study underscores the need for better participant preparation and stronger convenor support.

⇒ We suggest a systematic evaluation after each TF to inform ongoing adjustments.

INTRODUCTION

The European Alliance of Associations for Rheumatology (EULAR) forms task forces (TF) to develop recommendations and points to consider with adherence to the principles of equality, diversity and inclusion.[1] The EULAR TF standard operating procedures (SOP) is a living document, originally published in 2004 and updated in 2022.[2 3] The original version included four categories of members (ie, traditional members): the convenor, the expert members, a methodologist and a fellow for the literature search.[2] In 2014, the

inclusion of new members was added, comprising at least three representative members—one health professional in rheumatology (HPR) and two patient research partners (PRP), and two junior members from the Emerging EULAR Network (EMEUNET, a network of young clinicians and researchers in rheumatology, part of EULAR as a distinct committee), allowing contribution from all EULAR communities.[4 5]

Incorporating members with different perspectives has been associated with better patient care.[6] This approach is also expected to increase the productivity of the TF.[7] Nevertheless, the contribution of the junior and representative members in a TF has never been evaluated. Our objective was to evaluate their preparation and participation in TFs as compared with other traditional members.

METHODS

A survey was developed by EULAR and EMEUNET members and comprised 49 questions in three categories: (1) demographics and TF information, (2) TF preparation, (3) TF participation (online supplemental materials). The survey used multiple-choice questions, continuous rating scales questions from 0 (fully disagree) to 100 (fully agree), or open-ended questions (online supplemental materials).

The survey, using SurveyMonkey, was disseminated via email in spring 2023. Snowball sampling was used to reach HPR, the People with Arthritis and Rheumatism in Europe, and members of the EMEUNET community who had participated in a TF, in addition to other members of recent TFs.

For participants who participated in more than one TF, the questions were stratified. They were asked about: (1) the barriers to participation in the TF where they felt least able to contribute actively, and (2) the facilitators for participation in the TF where they felt they could contribute the most.

Categorical variables were presented using number and percentage and numerical variables (primarily comprising 0–100 rating scales) using median scores (IQR). Comparisons were performed using χ^2, Wilcoxon test or t-test for paired data, as appropriate. A p value of <0.05 was considered statistically significant. All analyses were performed using R V.4.3.0. Surveys were anonymous. All participants' information were securely stored by SurveyMonkey in their SOC two accredited data centres that adhere to security and technical best practices.

RESULTS

We included 77 participants from 24 countries, 48/77 (62%) were women, age at survey completion was between 26 and 35 years for 15/77 (19%), between 36 and 45 years for 22/77 (29%), between 46 and 55 for 14/77 (18%) and more than 55 for 26/77 (34%).

Respondents identified themselves as follows: 43/77 (56%) rheumatologists, 32/77 (42%) researchers, 19/77 (25%) HPR and 15/77 (19%) patients. 25 of 77 (27%) had participated in 1 TF, 37/77 (48%) in 2–5 TFs and 16/77 (21%) in >5 TFs. Those who had participated as junior or representative members were 46/77 (60%, 23/77 EMEUNET, 10/77 HPR and 14/77 PRP); 13/77 (17%) had participated as convenors, 7/77 (9%) as methodologists, 20/77 (26%) as fellows and 50/77 (65%) as expert TF members. Junior and representative members reported feeling less clear about their roles compared with other TF members (median score 80 (IQR 66, 90) vs 88.5 (IQR 72.8, 99), p=0.048).

Among 14/74 (19%) participants who felt unprepared for their first TF, 10/74 were junior or representative members (4/74 junior members, 3/74 HPR and 3/74 PRP). Participants who felt prepared had read the SOP before TF more often (39/60, 65%) compared with those who did not feel prepared (5/14, 36%), p=0.07. Participants who reported that they felt unprepared stated that they would have wanted meetings beforehand (8/14, 57%), or written documents (5/14, 36%), half of them having read the SOP before the TF.

Barriers for participation according to the role in the TF are represented in figure 1. Additionally, junior and representative members were more 'afraid to look stupid' (median score 30.0 (IQR 15.0, 57.0) vs 10.0 (IQR 1.0, 51.0), p=0.04) and feared 'not being expert enough' (median score 50.0 (IQR 17.0, 70.0) vs 20.0 (IQR 3.8.0, 50.5), p=0.07). Four participants (three patients, one HPR) felt their contribution was limited by the scientific aspect. No difference was observed for feeling unsafe (median score 7 (IQR 1, 34) vs 11.0 (IQR 0.0, 29.0), p>0.99). 10 participants reported that they had felt unwelcomed (four patients, three HPR, one junior and two expert TF members). Comments were raised (n=11) about members with 'strong personalities' who had limited their participation by 'not inviting them to speak', 'interrupted' them or 'influenced the open label voting system'. Other reported barriers were 'the online format' (n=4), the 'limited time' (n=2) and 'medical language' (n=3).

Compared with traditional members, junior and representative members reported feeling that their participation was more facilitated by the convenor directly asking for their opinions, although not statistically significant (median score 79.5 (IQR 50.0, 98.8) vs 67.5 (IQR 13.5, 97.8), p=0.15), figure 2. Junior and representative members were less likely (15/28 (54%)) to report that the convenor facilitated their participation the most compared with traditional members (22/31 (71%), p=0.17). Interaction was facilitated by experience, expertise and preparation (54%), feeling supported or specifically spoken to by the convenor (42%), and perception of a clear role (12%).

Responders in multiple TFs participated more frequently as a junior or representative member in the TF they were the least active in compared with the one they were most active in (24/50 (48%) vs 16/48 (33%), p=0.13). When comparing the TF they participated the

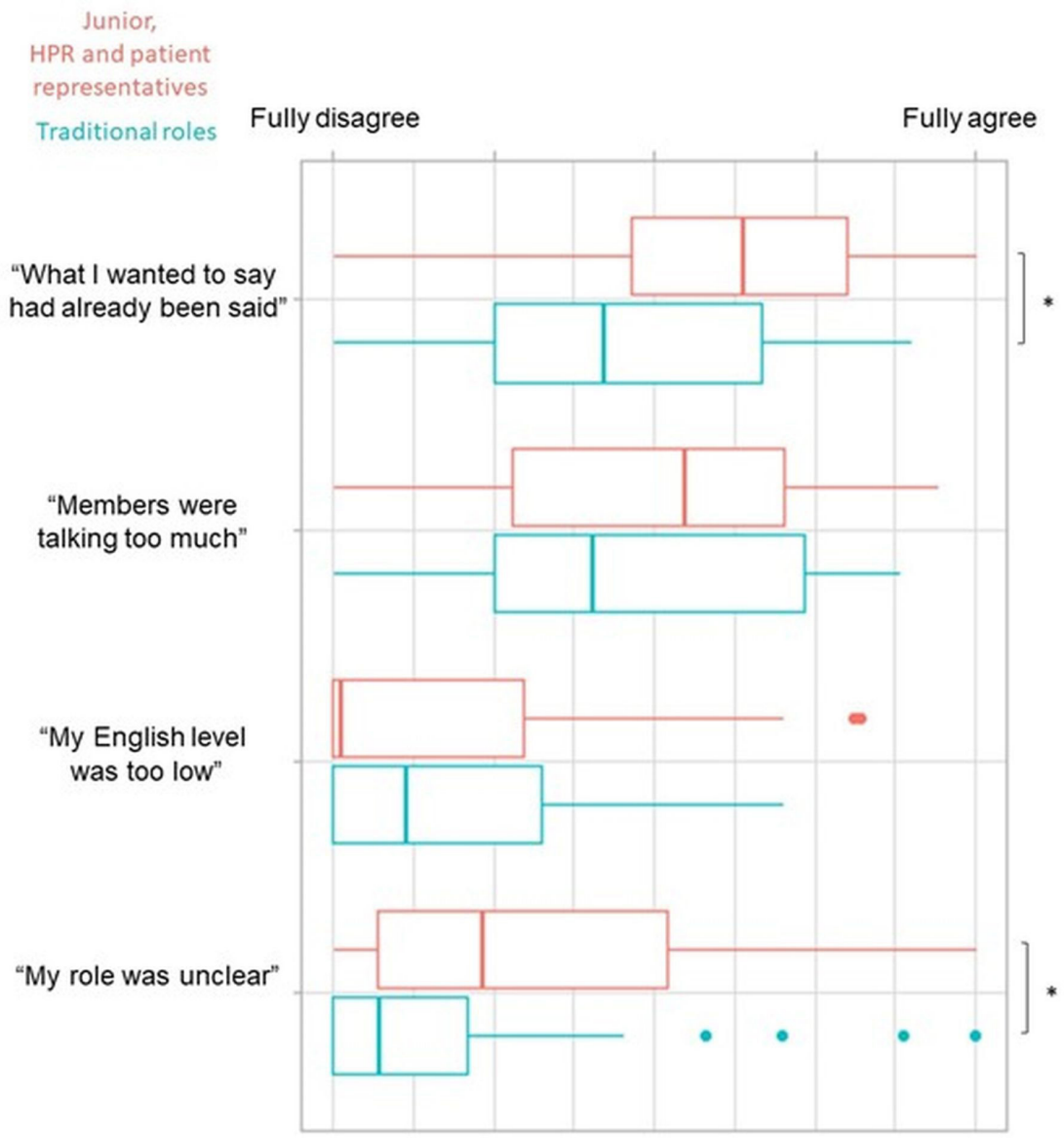

Figure 1 Barriers to participation in a European Alliance of Associations for Rheumatology task force stratified by the type of role. Type of role in the TF were stratified by traditional type of roles (convenor, methodologist, fellow and expert TF member) and junior/representative (HPR, patients) type of roles. Rating scale questions were used to evaluate facilitators with scores ranging from 0=fully disagree to 100=fully agree. Graphs show the distribution of the answers. Box plots represent the 25th, 50th and 75th percentile, whiskers maximum and minimum answers, and dots outliers. *p<0.05. HPR, health professional in rheumatology; TF, task force.

most to the one they participated the least, there was no difference regarding the mean number of participants in the TF (23.0±6.8 vs 26.2±9.3, respectively) or the gender of the convenor (53% vs 54%, respectively).

Participants viewed responsibility for active meeting participation as shared between the convenor and TF members. On a scale from 0 (being in favour of the TF member's own responsibility) to 100 (being in favour of the convenor's responsibility)), the median score was 52 (IQR 50, 65). Compared other TF members, convenors and methodologists were more likely to believe responsibility for active meeting participation fell on the convenor; median score for convenors and methodologists was 66 (IQR 58.5, 73) compared with 51 (IQR 50, 60.8) for other TF members (p=0.01, figure 3).

DISCUSSION

In this first study investigating feedback from EULAR TF members, junior and representative members felt less involved and less comfortable to actively participate in a TF compared with the other traditional members. The current SOP does not seem to effectively prepare junior and representative members to the TF.

EULAR made the inclusion of junior and representatives members mandatory to each EULAR TF since

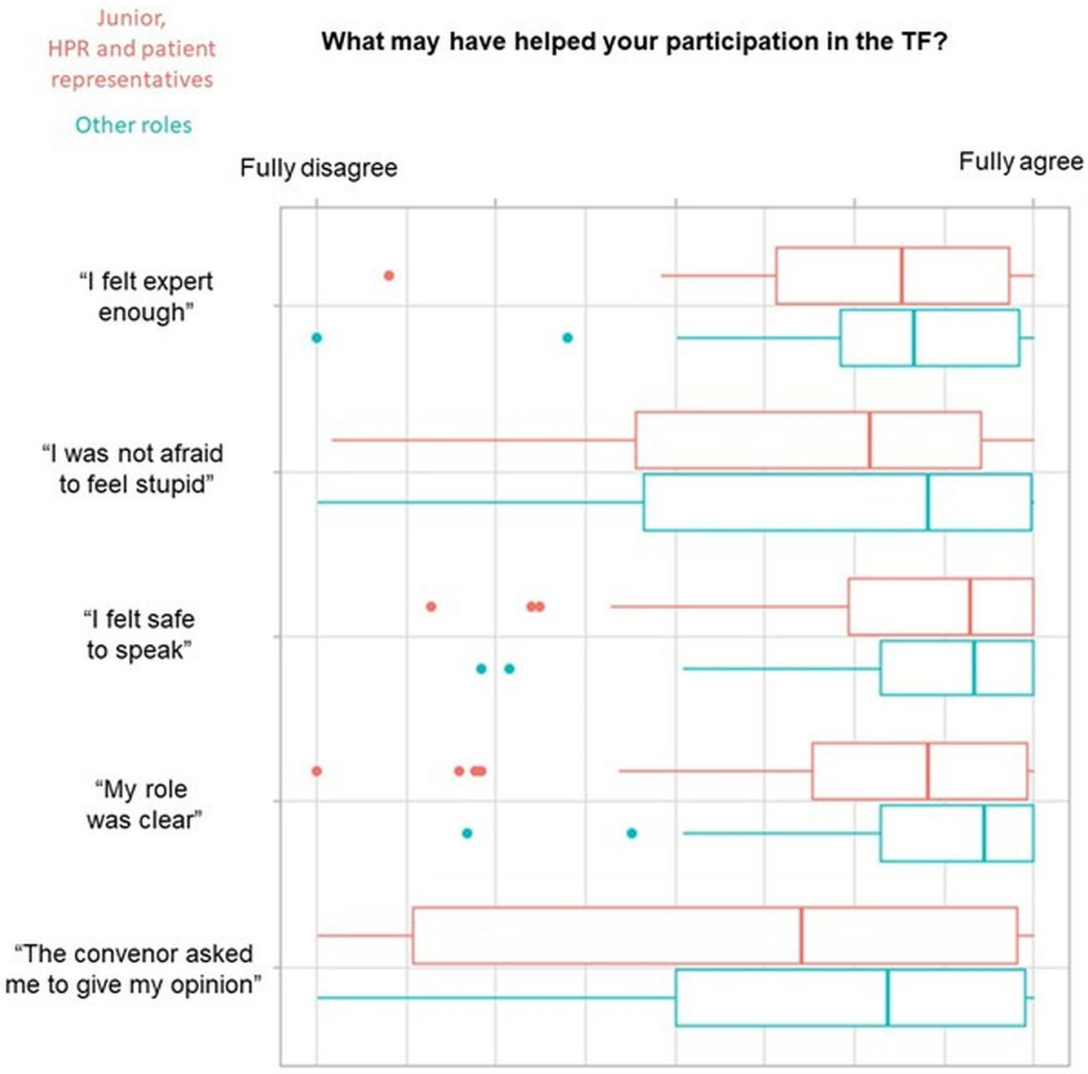

Figure 2 Facilitators for participation in a European Alliance of Associations for Rheumatology task force stratified by the type of role. Type of role in the TF were stratified by traditional type of roles (convenor, methodologist, fellow and expert TF member) and junior/representative (HPR, patients) type of roles. Rating scale questions were used to evaluate facilitators with scores ranging from 0=fully disagree to 100=fully agree. Graphs show the distribution of the answers. Box plots represent the 25th, 50th and 75th percentile, whiskers maximum and minimum answers, and dots outliers. HPR, health professional in rheumatology; TF, task force.

2014,[4] aligning with findings that diverse viewpoints including patients in elaboration of clinical practice guidelines was a key component to better care, more relevant outcomes and promoted patient adherence to treatment.[8–10] However, our results showed that junior and representative members face more difficulties than other TF members. It is in EULAR's interest to identify and dismantle these barriers to optimise contribution from all TF members.

Training is the most frequently reported facilitator for the participation of representative members.[10] In 2011, EULAR suggested that the convenor should give a clear description of the expected contribution of patients participating in a TF and offer them appropriate training.[5] Still, our results demonstrated that junior and representative members did not feel sufficiently prepared. In January 2022, EMEUNET provided tailored SOPs for junior members (online supplemental materials). However, this document did not provide detailed information about expected TF preparation or participation. Several solutions have previously been suggested such as preliminary meetings or training, and assistance for scientific terminology.[10] To ensure all task force members have access to helpful resources, it will be helpful to have short and engaging instructional videos or webinars. These resources could address common barriers and potential facilitators for active participation and an informed membership. If needed, we encourage all TF members to contact the convenor upfront for clarification regarding their expected role.

Support is another facilitator for active participation.[10] In order to maximise contribution from every TF's member, uncooperative behaviours should be avoided. While EULAR TFs were generally seen as safe

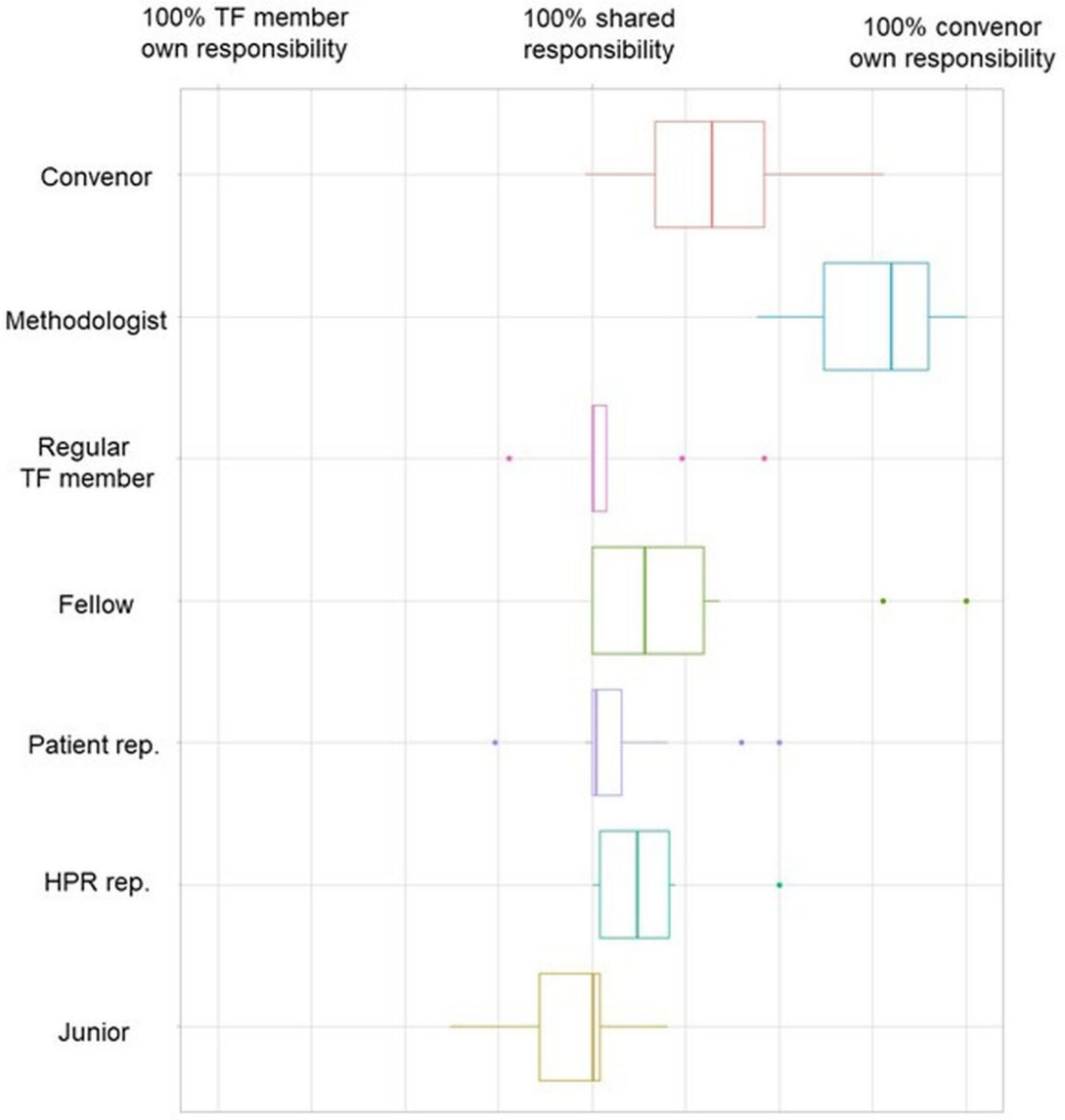

Figure 3 Repartition of responsibility for making members actively participate during the task force meetings. Participants were asked to answer to a continuous scale rating question from 0 being 100% the TF member own responsibility, to 100 being 100% the convenor own responsibility (50 being indicated as 100% shared responsibilities). Graphs show the distribution of the answers according to the role in the TF. Box plots represent the 25th, 50th and 75th percentile, whiskers maximum and minimum answers, and dots outliers. HPR, health professional in rheumatology; TF, task force.

environments, unsupportive strong personalities were reported, potentially affecting participation and votes for level of agreement with the developed recommendations. Switching to a blinded voting system and allowing each member to privately share concerns about excessive dominance should be considered.

Participation in a TF is not limited to scientific expertise but include other aspects such as adapting evidence-based medicine to practical care, pointing out inequities or making the scientific part more understandable.[10] The value of diverse perspectives should be systematically presented in advance to every member, including the convenors. Our current survey, did not allow us to analyse the specific influence of different TF members on the topic. This is an aspect that warrants further investigation in future evaluations of TFs work.

In addition to bias inherent to online surveys, the small sample size did not allow subgroup analyses to identify specific barriers and facilitators for each type of members. As data on the timing of the TF was not collected, and thus we could not analyse changes in barriers and facilitators over time. Among participants, 30/77 (52%) were older than 45 years which may have limited the evaluation of barriers and facilitators of early career members. In our survey, we could not analyse the impact of the topic of the TF on member's participation. This should be evaluated in larger and more systematic evaluations of TFs. However, this is the first study investigating feedback from EULAR TF members. Assessing the participation of each TF member and the impact of junior/representative members on the recommendations is an unmet need.[10] The elaboration of a systematic standardised

survey after each TF evaluating the contribution of each TF member could be considered for the next SOP. This would enable collection of more detailed data to facilitate comprehensive analyses for different member types and how responses changed over time.

In summary, in EULAR TFs, junior, PRP and HPR members faced specific barriers (uncertain role, inadequate preparation, and difficulties for engaging actively) that differed from those experienced by traditional TF members. Our study highlighted the need for enhanced preparation of participants and more support from the convenor. Furthermore, we suggest a systematic evaluation after each TF allowing further adjustment.

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Acknowledgements We would like to thank all the participants to the survey.

Contributors P-AJ was responsible for data curation, formal analysis, methodology, software and writing of the original draft. TWK, LFP-G, EF-M, SM, PB, JP, RJOF, TPMVV, MN, UK and RL were responsible for conceptualisation, data curation, reviewing and editing the manuscript. KL and MdH were responsible for conceptualisation, data curation, formal analysis, methodology and writing of the original draft. All authors had final responsibility for the decision to submit for publication.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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