ISMPP member survey on patient engagement in medical publications: Reported experience

Poster 41

Susan Scott,[a] Emma Phillips,[b] Nichola Gokool[c]

[a]Scott Pharma Solutions Ltd, Baldock, UK;
[b]Costello Medical, Cambridge, UK;
[c]Parexel International, Worthing, UK

ISMPP Patient Engagement Task Force

CALL TO ACTION

FOR ISMPP

Survey respondents suggested several actions ISMPP could take to encourage patient engagement in medical publications:

- **Provide resources, forums, and training on best practice**
- **Provide suggestions and examples of how to engage with and onboard patients**
- **Compile evidence of the impact of patient engagement**

FOR ALL MEDICAL PUBLICATION PROFESSIONALS

- **Build long-term, meaningful relationships with patient advocacy groups to develop trust, improve multi-stakeholder collaborations, and gain access to patient representatives**
- **Provide training and resources to all stakeholders—sponsors, healthcare professional authors, and patients themselves—to support patients to be fully involved and to maximize their value in medical publication development**

INTRODUCTION

- Patient involvement in medical research and communication, including in publications, adds value by ensuring the patient perspective is considered and medicines are developed to meet unmet patient need.[1]
- The International Society for Medical Publication Professionals (ISMPP) Patient Engagement Task Force (PETF) was created in 2023 to:
  - Develop education and best practice guidance on partnering with patients and patient advocacy groups (PAGs) when creating medical publications and communications
  - Build outreach with PAGs to collaborate on the above activities
- Our objective was to gather experience and insights from the ISMPP membership on patient engagement in medical publications, with the aim of identifying areas where ISMPP can promote, develop, and support patient engagement in future publications activities.

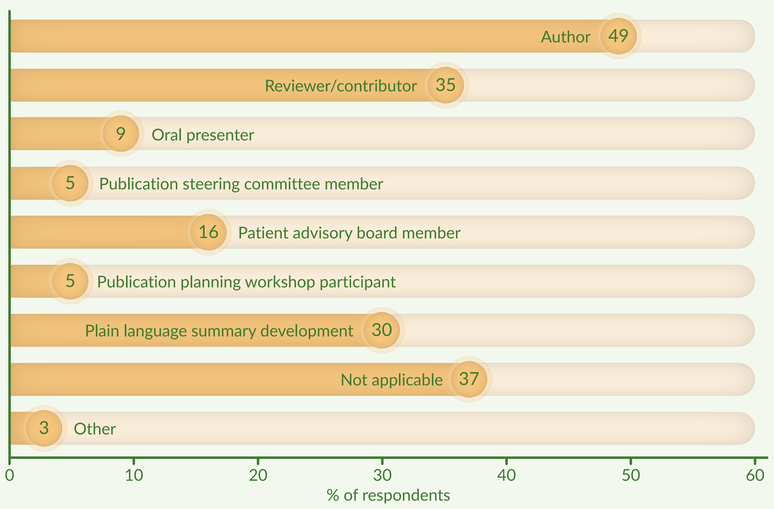
METHODS

- The ISMPP PETF designed an online, anonymous survey asking respondents to report their experience of patient engagement in medical publications, including challenges and proposed solutions, and share ideas for support from ISMPP.
- Comprising 20 multiple-choice and open-ended questions, the survey was circulated to all ISMPP members via the SurveyMonkey platform between September 30, 2024, and October 15, 2024.
- Results were collated and descriptive statistics were provided by the platform.
- Generative artificial intelligence was used to summarize open-ended questions.

RESULTS

- 347 people replied to the survey. Most respondents (88%) were from Europe or North America, with 89% working for pharmaceutical companies or medical communication agencies.
- Respondents specialized in a range of therapy areas, including oncology (50%), immunology (37%), rare diseases (32%), and neurology (28%).
- Nearly half of all respondents (48%, 165/347) reported involvement where patients directly contributed to medical publication activities. Their various roles are shown in **Figure 1**.

Figure 1. Role of patients in medical publications (N = 172)



- More than half of respondents had not paid patients for their involvement (52%, 92/177).
- Most respondents (61%, 105/171) reported they had not provided publication training materials to patients.

Challenges

- Barriers to patient engagement were both internal and external (**Table 1**).

Table 1. Barriers to patient engagement

Internal barriers
Compliance concerns
Time constraints
Lack of standard process
Limited sponsor understanding on how to engage patients
External barriers
Access to patients
Maximizing inclusivity of patient group
Patients' knowledge of publications

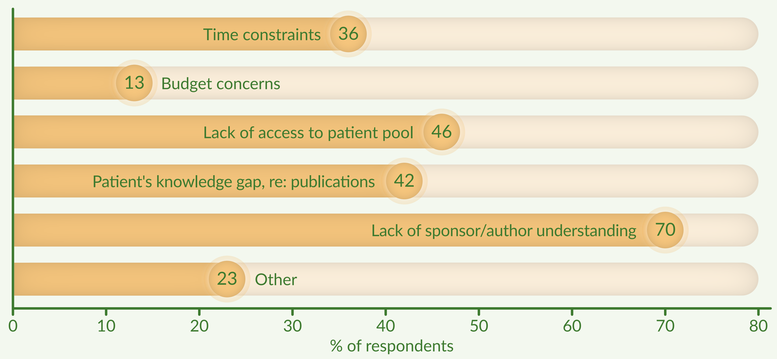
Survey respondent quotes

"Lack of internal SOP. Lack of rationale to do so based on ICMJE criteria. Lack of involvement of patient/PAGs in clinical study protocol."

"Lack of overall guidance to make compliance departments feel safe about allowing this."

- Most common key challenges experienced by respondents when engaging patients in medical publication activities are shown in **Figure 2**.

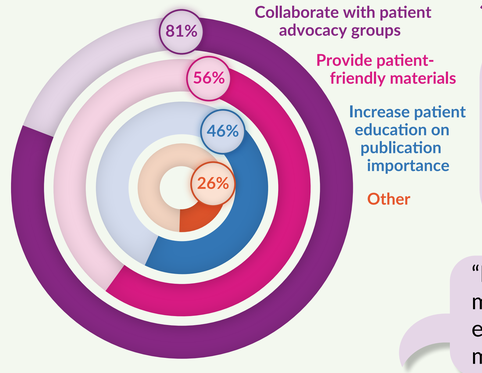
Figure 2. Key challenges in patient engagement in medical publications (N = 171)



Suggestions for overcoming challenges

- Survey respondents suggested a number of actions to address the challenges (**Figure 3**).

Figure 3. Proposed actions to overcome challenges (N = 167)



Survey respondent quotes

"Increase education for sponsoring companies on the fact that not only can patient involvement be compliant, it is essential."

"Educating Legal/Compliance members in the value of engaging with patients for medical publications"

- Of 170 replies, many respondents cited following existing guidelines:
  - Good Publication Practice 2022 (91%)[2]
  - Taylor & Francis PLSP Guidelines (37%)[3]
  - EFPIA Guidelines (20%)[4]
  - Cochrane PLS standards (19%)[5]

CONCLUSIONS

- **While challenges exist, medical publication leaders can support increased patient engagement through clear guidelines and training of sponsors, authors and patients.**
- **Working with patient advocacy groups to build patient relationships will boost the patient voice in medical publications.**

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