

Fostering peer-reviewed publication of patient engagement activities: multistakeholder perspectives on priorities, motivators, and challenges



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BACKGROUND

- Patient engagement efforts are becoming increasingly important in healthcare, across all stages of research and decision-making,¹ with growing support for the need to co-create healthcare solutions working with patients as partners
- The Patient Engagement Open Forum (PEOF) is organized as a series of events involving the patient engagement community all year round. PEOF provides continual virtual sessions throughout the year, as well as a live, in-person event²
 - Participants include patients, industry, regulators, policymakers, payors, and researchers
- PEOF is steered by and organized as a collaborative venture by Patient Focused Medicines Development (PFMD),³ the European Patients' Forum (EPF),⁴ and the European Patients' Academy on Therapeutic Innovation (EUPATI)⁵
- Publications describing patient engagement efforts are limited, despite substantial growth in the number and diversity of these efforts
- There is a need to share patient engagement methodologies, learnings, best practices, and outcomes, and to make these more visible to scientific and patient communities, and to all who are active in patient engagement. Peer-reviewed publications and congress presentations are validated methods for such dissemination

OBJECTIVE

- To explore priorities, motivators, and challenges to the development of publications focusing on patient engagement activities

METHODS

- We conducted surveys virtually using an online tool (August 18 to September 25, 2023) and during a live PEOF session (October 3, 2023)
- Participants were active in patient engagement and were invited through PEOF networks and social media outreach
- The online survey was developed to identify the different types of participants and their affiliations, the level of patient engagement experience of respondents, the priority of patient engagement publications, as well as motivators and limitations for the development of patient engagement publications
- The live PEOF survey was developed to expand the dialogue with participants, reconfirm online survey results and capture additional granularity on motivators and limitations. The live survey was also used to identify what participants believe is needed to support systematic development of patient engagement publications

CONCLUSIONS

- Our survey results demonstrate that developing publications describing the process and insights from patient engagement activities is a priority, but challenges exist
- Efforts should focus on providing resources and practical 'How-To' guidance to foster more systematic development of peer-reviewed patient engagement publications

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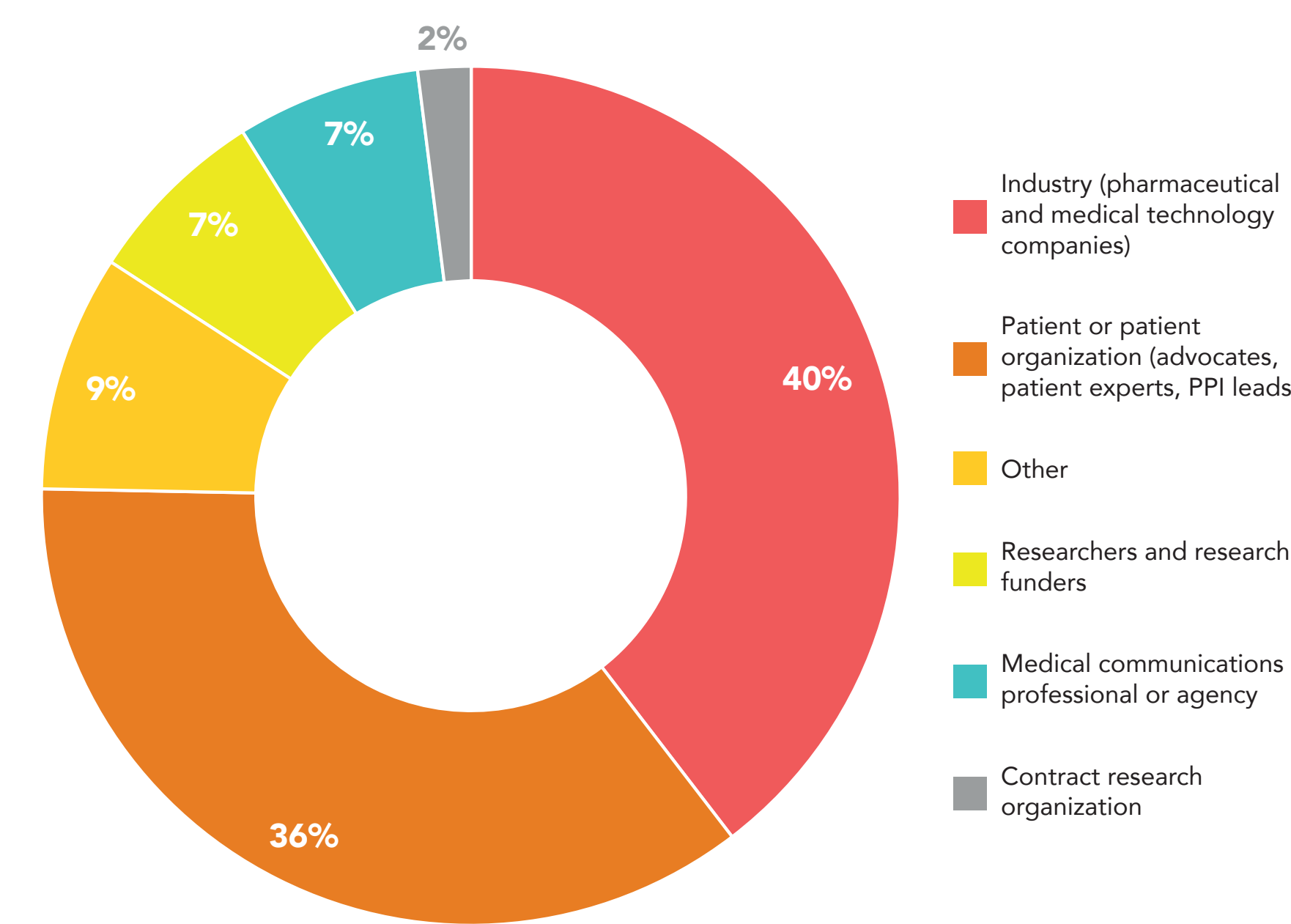
RESULTS

- A total of 92 respondents participated, 51 online and 41 at the live PEOF session. There was potential for overlap between online and live respondents

Interested groups and publication experience

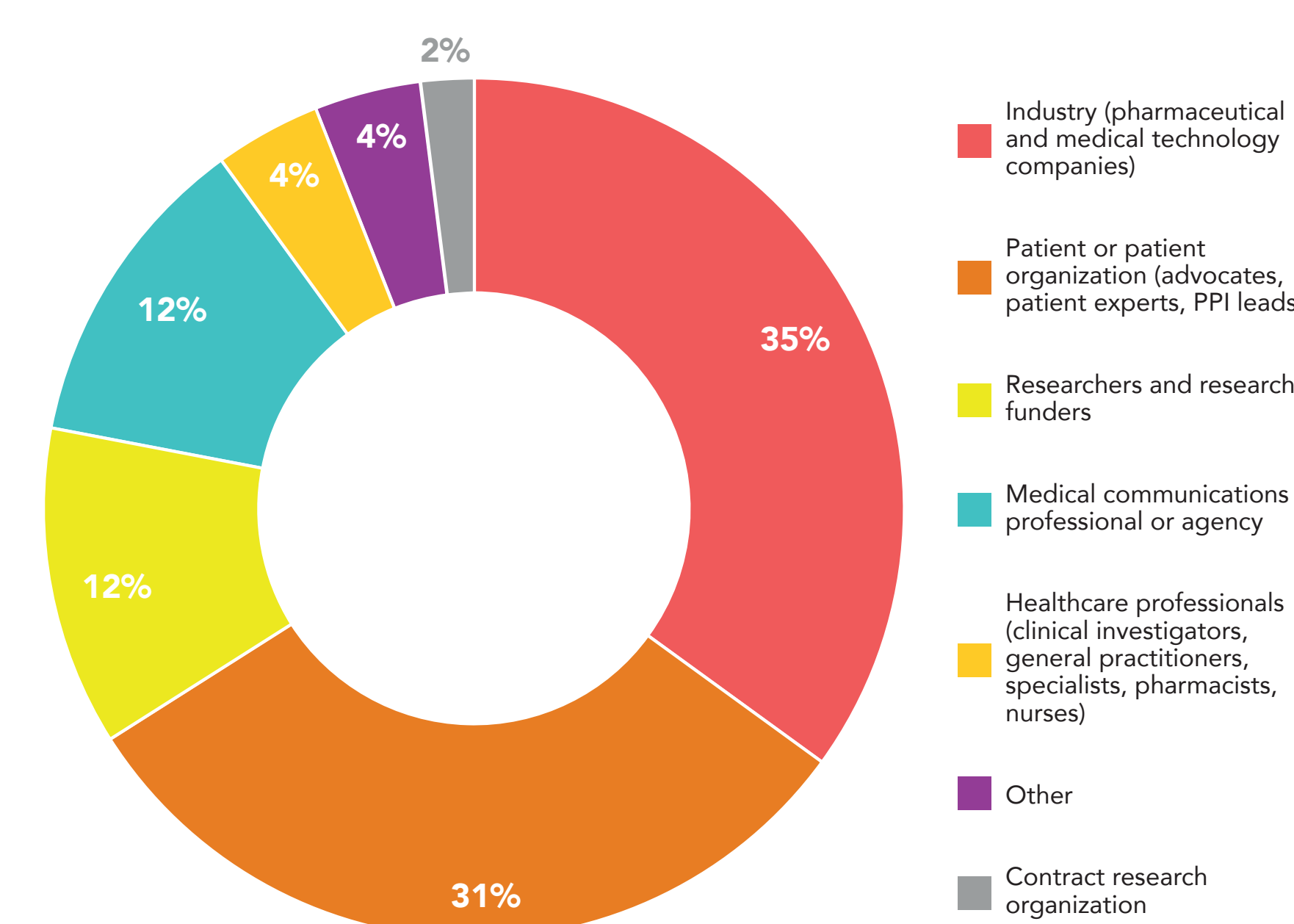
- Interested groups responding to the survey (online and live) were pharmaceutical/medical technology (40%), patients/patient organizations (36%), researchers/research funders (7%), medical communication agencies (7%), contract research organizations (2%), and other (9%) (Figure 1A)
- There was a similar diversity and proportion of interested groups in both online (Figure 1B) and live (Figure 1C) surveys
- More than half of participants in the online survey (59%) had experience of patient engagement publications (Figure 2)

Figure 1A. Interested groups participating in the online and live surveys combined (92 respondents)



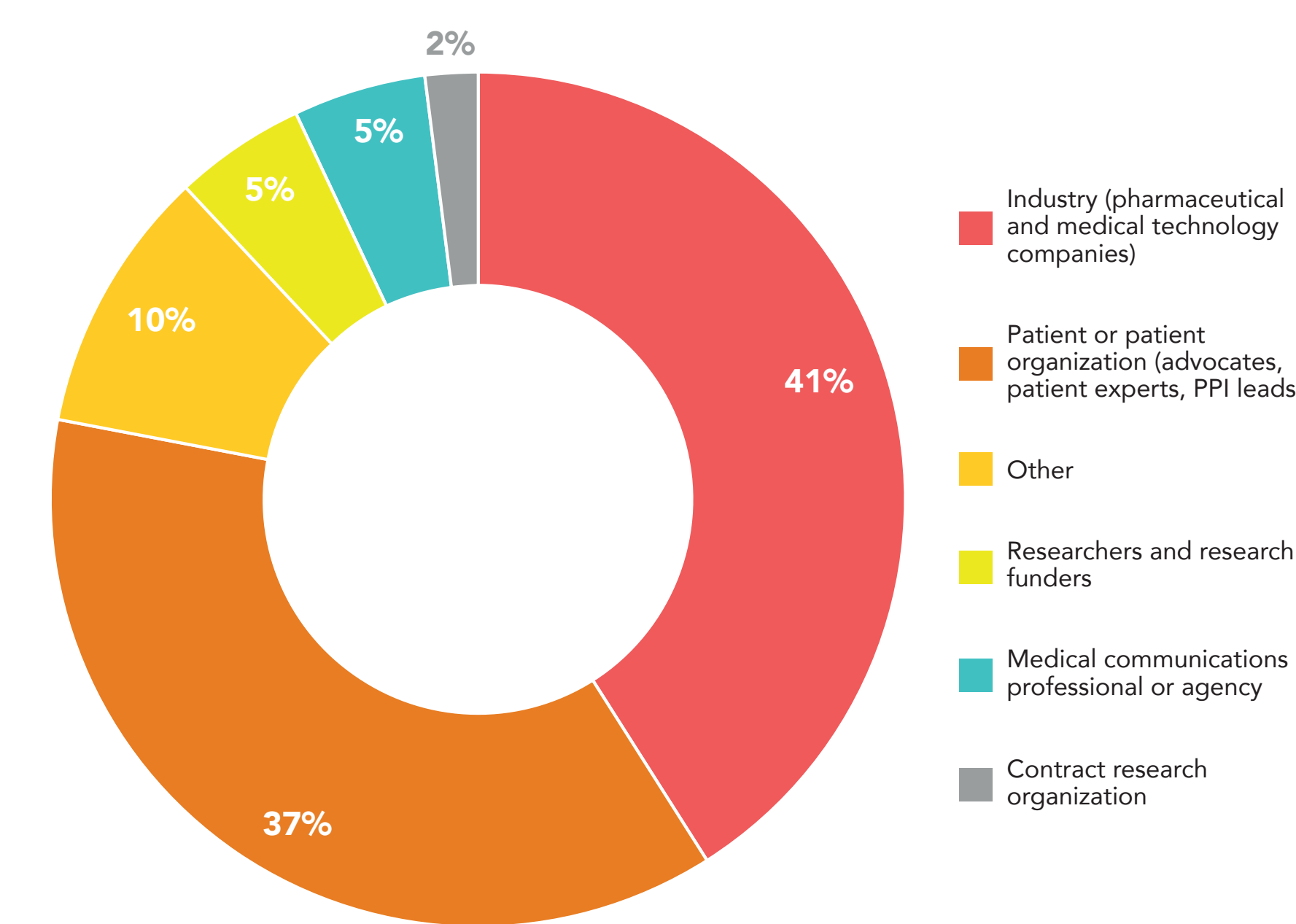
PPI, patient and public involvement.

Figure 1B. Interested groups participating in the online survey (51 respondents)



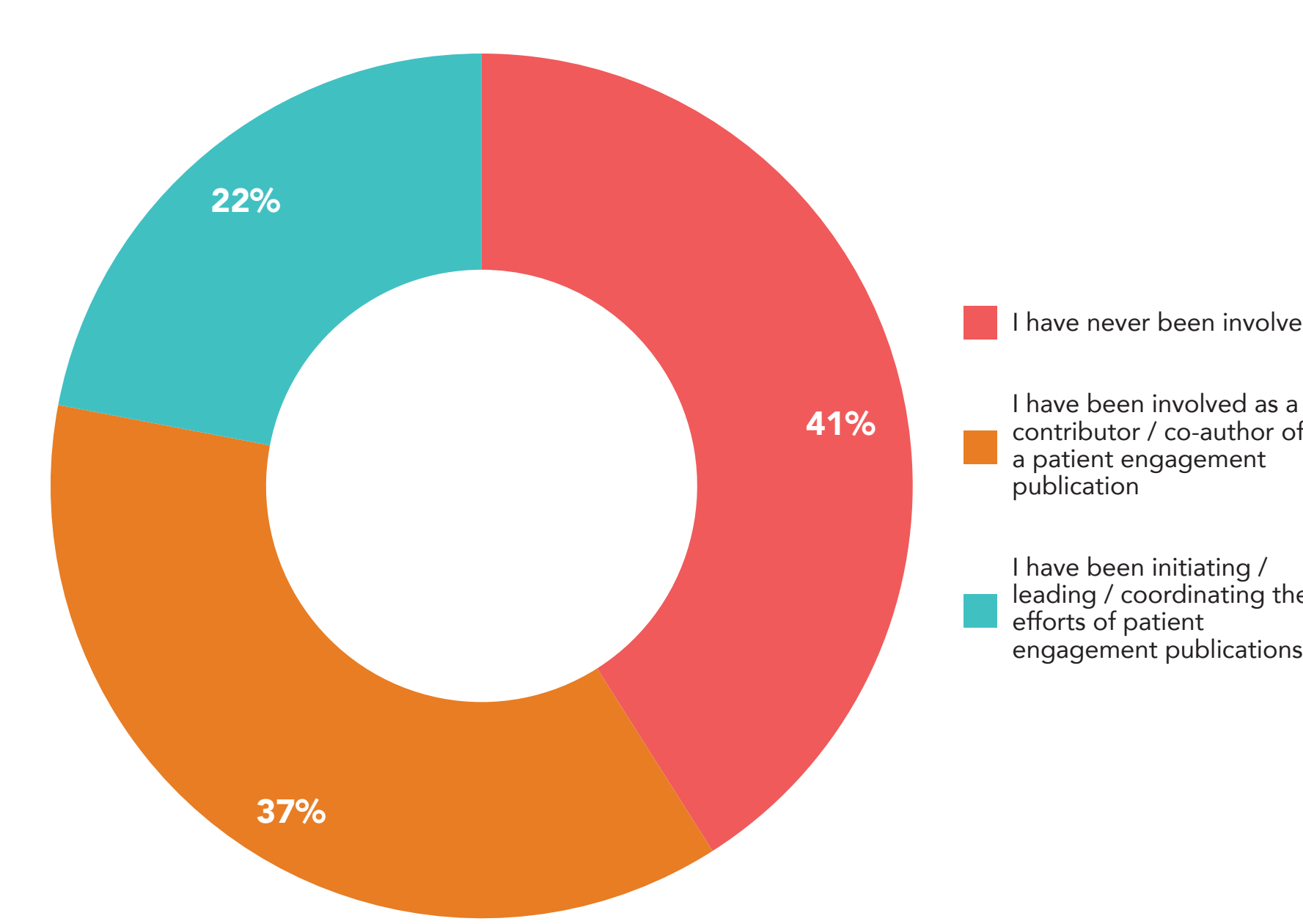
PPI, patient and public involvement.

Figure 1C. Interested groups participating in the live survey (41 respondents)



PPI, patient and public involvement.

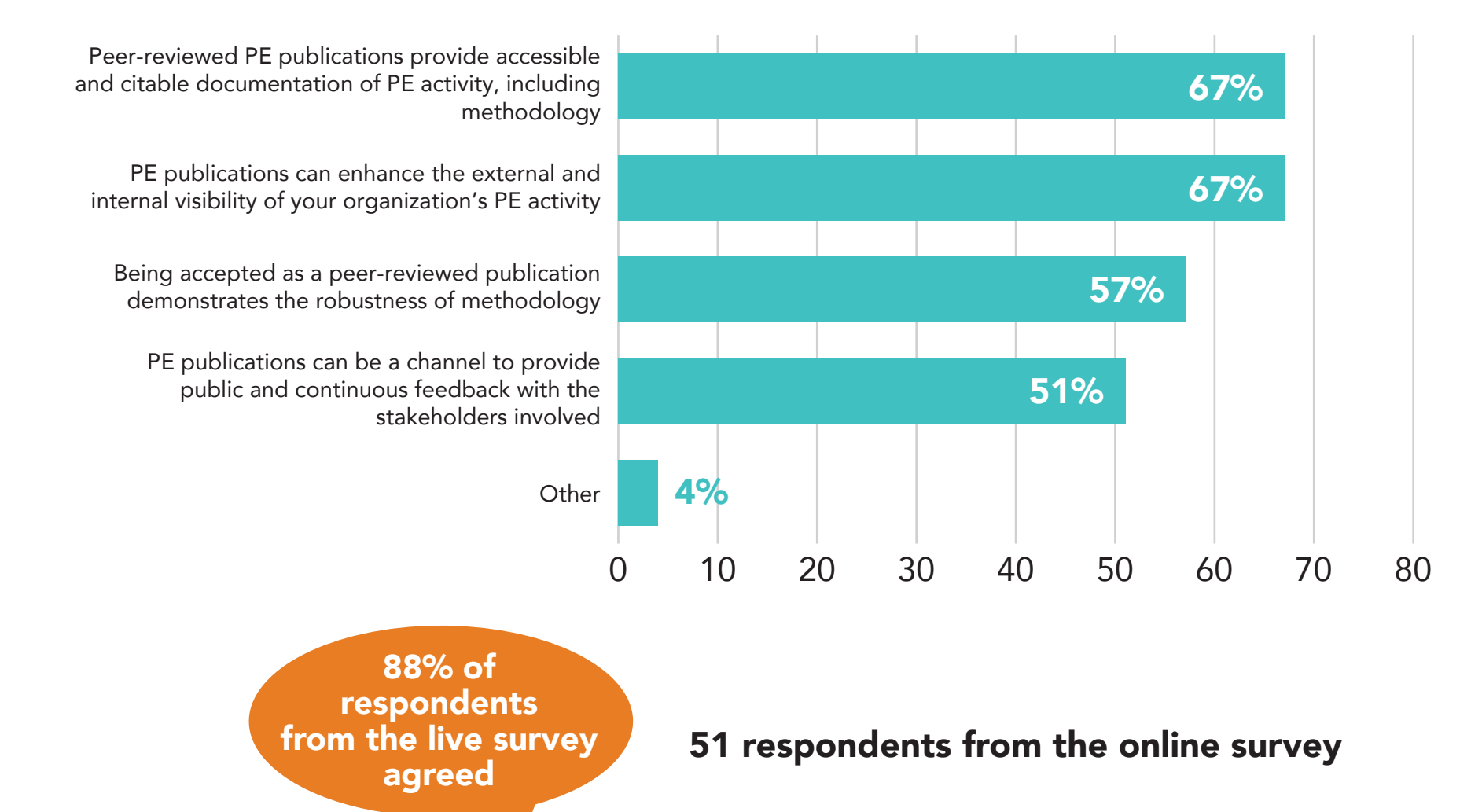
Figure 2. Experience with patient engagement publications among participants in the online survey (51 respondents)



Priorities, motivators, and challenges for patient engagement publications

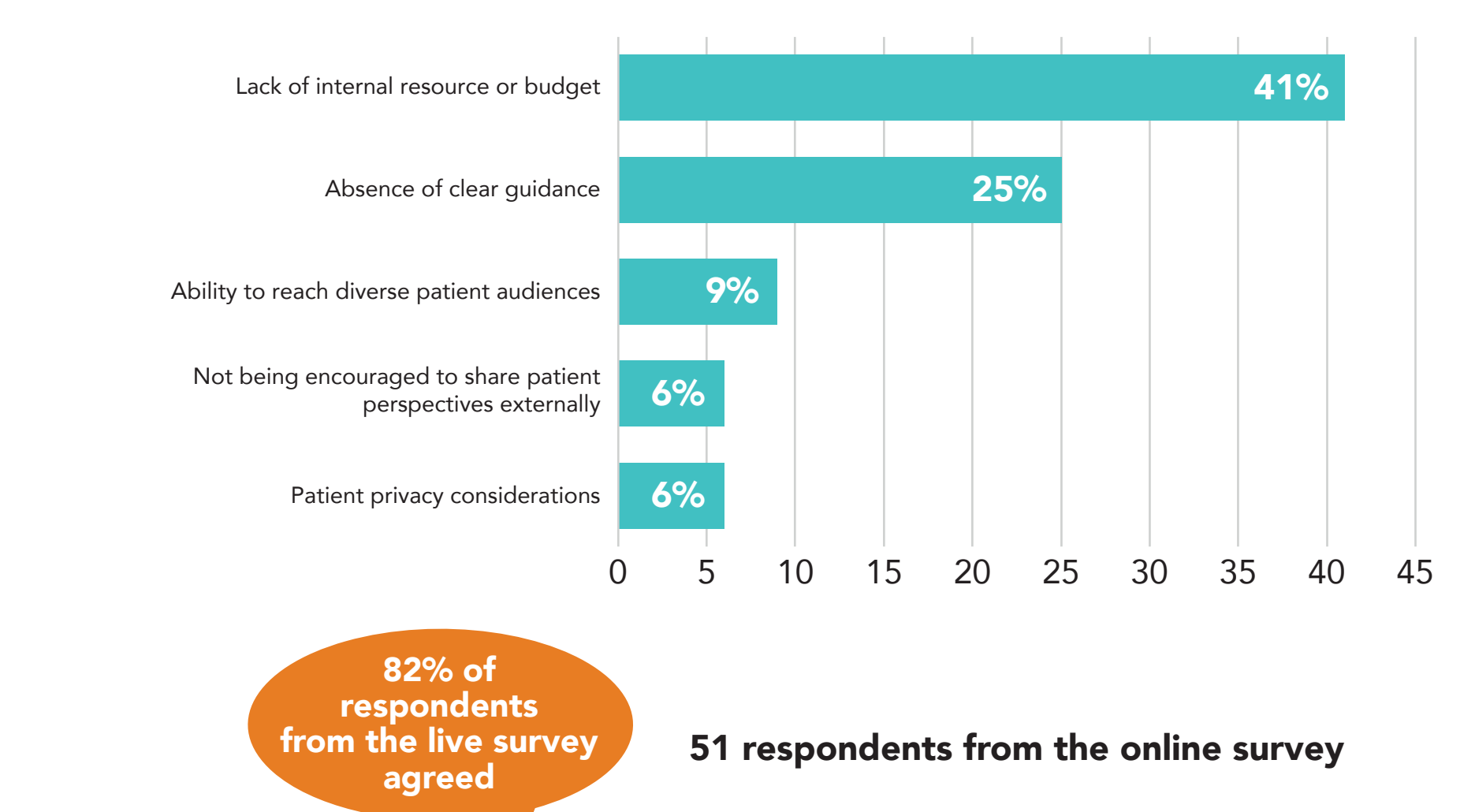
- Among respondents from the online survey, 61% indicated that patient engagement publications were a high priority, 31% a medium priority, 6% a low priority, and 2% not a priority at all
- Online respondents indicated that key motivators for patient engagement publications were providing accessible documentation (67%), enhancing visibility (67%), demonstrating robustness of methodology (57%), and providing feedback to interested parties (51%) (Figure 3)
 - Among respondents from the live survey, 88% agreed
- Online respondents mentioned key challenges as lack of internal resource/budget (41%), absence of clear guidance (25%), ability to reach diverse patient audiences (9%), not being encouraged to share patient perspectives externally (6%), and patient privacy considerations (6%) (Figure 4)
 - Among respondents from the live survey, 82% agreed

Figure 3. Motivators for patient engagement publications indicated by participants in the online survey



Other motivators included academic acceptance and sharing best practice. PE, patient engagement.

Figure 4. Limitations for patient engagement publications indicated by participants in the online survey



Other limitations included potentially lengthy peer-review processes and competing research priorities.

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DISCLOSURES

DR is a full-time employee of Five02 Labs, Inc., which helps people and organizations engage patients in their research projects and initiatives (including publications); and is the volunteer Vice President of the Canadian Arthritis Patient Alliance, an organization that receives the majority of its funding through independent grants from pharmaceutical companies. LD is a co-founder and owner of Becaris Publishing Ltd. She undertakes paid and unpaid consultancy for stakeholders in the healthcare and academic publishing industry, and receives an honorarium as a journal Editor-in-Chief. LS is an employee of Janssen Scientific Affairs, LLC. A-MH and IS are employees of Twist Medical, LLC.