



# Patient engagement (PE) in publications

ISMPP PATIENT ENGAGEMENT TASKFORCE (PETF)

**Strategic Plan**

2024–2025



# Strategic plan: Approach

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# The mission and vision

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## MISSION

To facilitate  
patient  
engagement  
throughout the  
publication  
lifecycle

## VISION

Patients  
established as a  
key collaborator  
in industry-  
sponsored  
publications

# PE in publications: Opportunities identified by the PETF

Patients can play a key role as collaborators in many aspects of medical publications including:

## For specific publication plans

- As idea generators and planners: Conceptualizing and planning publications
- As content collaborators/creators: Collaborating, co-creating, and authoring publications
- As readers and sharers: Disseminating and digesting publications

## As advisors to guide our profession

- Guiding/advising pharma industry regarding involving patients in publications
- Guiding/advancing ISMPP as our professional body
- Guiding/advising the discipline of medical publishing in general through contribution to industry-wide standards and guidelines, e.g. Good Publications Practice (GPP)

# PE in publications: Key challenges identified by the PETF

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- Lack of awareness of, and evidence for, the value
- Lack of awareness and understanding of the opportunities by both patients and industry
- Lack of understanding of the patient perspective regarding their engagement in publications
- Concerns about engaging with patients compliantly within a highly regulated environment
- Potential for engagement to be perceived as tokenistic
- Finding the right patients to partner with
- Lack of expert patients with specific skills who want to partner



# Strategic goals for the PETF



# Tactical plan to achieve the strategic goals for the PETF

## Focus groups

### Insights

To better understand the unmet needs of the ISMPP community

### Value and metrics

To explore ways to measure and communicate the value of PE in publications

### Awareness and communication

To raise awareness of PE in publications including existing resources

### Guidance and training

To develop new resources to facilitate PE in publications

### ISMPP partnerships

To establish ISMPP as a leader in the evolution of patient engagement in publications

5 focus groups were established within the PETF

Each focus groups was empowered to drive their own initiatives to meet the specific goals

Focus groups were encouraged to provide a regular update to the broader taskforce during scheduled calls

# Appendix: Points to note regarding scope

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Where “patients” are referred to, this can also include family, caregivers, patient advocates, and patient groups

This taskforce is specific to industry-sponsored publications to reflect the remit of ISMPP

Patient engagement in publications is often dependent on upstream events such as involvement in evidence generation, but this is beyond the scope

Patient engagement in publishing (including peer-review) is important, but influencing this is beyond the scope of this taskforce



# Appendix: Key stakeholders

Expert patient partners  
(advisors)

Pharma – publications/Medical  
affairs

Professional medical writers/  
editors (agency, freelance)

Enthusiastic potential patient  
collaborators

Pharma – compliance/legal

Pharma – all (clinical, R&D etc)

Professional societies  
(e.g., ISMPP leadership)

Patient advocacy groups

Pharma – senior management/  
budget holder

All HCPs/researchers including  
academic institutions

Lay audiences

Publishers/peer reviewers

HCP, healthcare professional; R&D, research and development