Developing a framework for patient involvement in publications

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Why did we create the framework?

- Involving patients in publications is recognized as valuable in the Good Publications Practice (GPP) 2022 guidelines¹
 - Patients are experts in the lived experience of a disease or condition, and can identify information relevant to other patients and help to ensure that concepts are comprehensible to a broad audience^{1,2}
- In light of the value that patients can add, journal editors-in-chief are becoming increasingly accepting of the inclusion of patients as publication authors³
- AstraZeneca places critical importance on the patient voice in science, delivery and communications
 - Development of an AstraZeneca-sponsored publication on patient experiences of living with heart failure⁴ identified the need for standardized guidance when working with patient authors
- Our aim was to develop a framework and toolkit to facilitate patient inclusion in AstraZeneca-sponsored publications, integrating evidence-based recommendations² and offering clear pathways to overcome perceived barriers

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How did we create the framework?

- Searches of peer-reviewed and grey literature provided the basis for the patient involvement in publications (PiiP) framework
- Consultation with key cross-functional internal stakeholders and a patient focus group helped to identify perceived barriers to patient involvement, define core framework principles and understand needs, resources and expectations
- An iterative drafting process was used to develop the framework and associated resources in response to feedback from a crossfunctional team of reviewers

Process for developing the framework

Landscape analysis

Peer-reviewed literature

Structured search of Ovid MEDLINE® for literature on patient involvement in publications

Patient-authored publications

Structured search of PubMed using author affiliations

Grey literature

 Manual searching of industry and patient engagement resource databases and news sites

Consultation

Internal consultation

- Survey of Publications Leads
- Individual and group interviews with internal stakeholders
- Cross-functional internal workshop to discuss core framework principles

Patient consultation

- Patient focus group and workshop with 8 patient ambassadors from 5 countries representing 5 therapy areas
- Identification of needs, resources and expectations

Iterative drafting

Development of draft framework and toolkit resources

Cross-functional review of draft

- Publications
- Patient Engagement
- Corporate Affairs
- Patient-Centred Science Patient ambassadors

Incorporation of comments

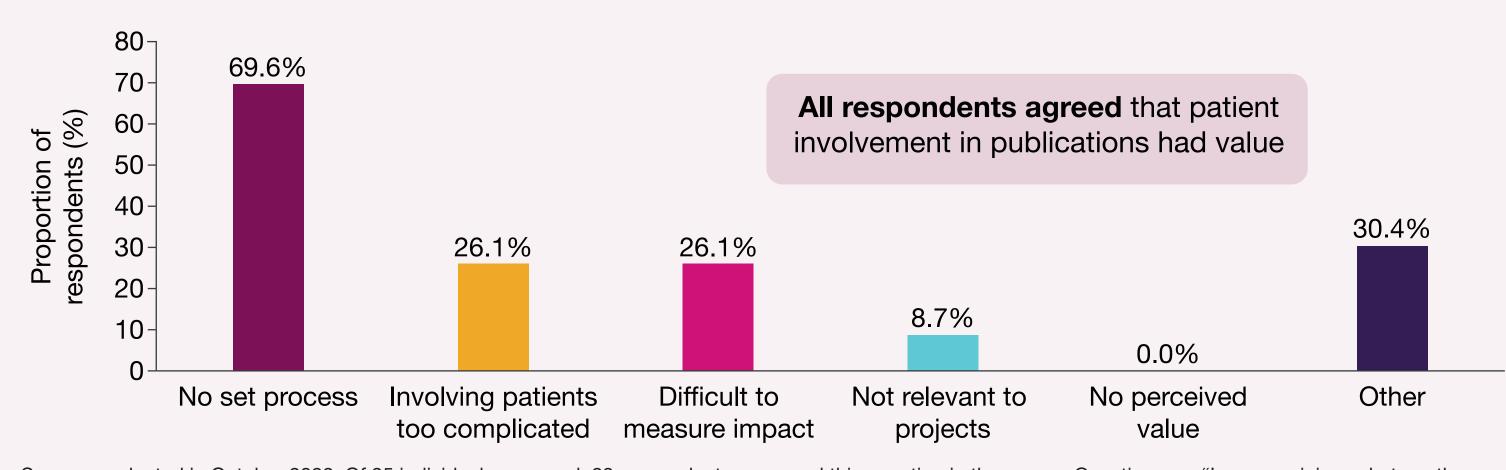
Dissemination

Global launch of framework and resource toolkit via internal communications platforms

Ongoing collection of feedback from internal users and patient authors/reviewers

What barriers were identified?

Results from a survey of 25 Publications Leads at AstraZeneca to identify barriers to patient involvement in publications



Survey conducted in October 2022. Of 25 individuals surveyed, 23 respondents answered this question in the survey. Question was "In your opinion, what are the current barriers to patient involvement in publications?" Answer was multiple choice where respondents could select multiple options, as well as entering free-text

Results from a focus group meeting with eight patient ambassadors to discuss patient involvement in publications



Barriers to accessing scientific publications:

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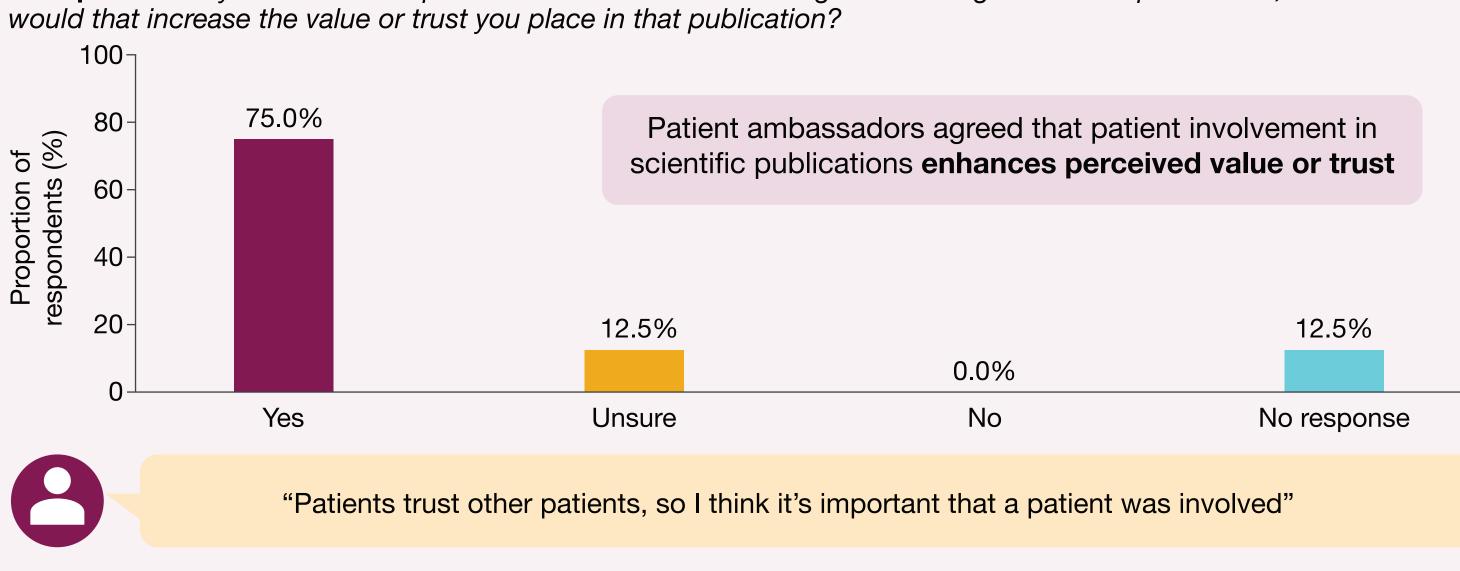


Non-patient friendly language and tone



Lack of accessible non-English content

Poll question: if you knew that a patient was involved in reviewing or authoring a scientific publication,



"The fact that a patient would see that there's actually a patient part of that review group ...

it's an important aspect"



"There is a huge distrust, a huge barrier between the patient and pharma, but involving patients in the publications makes it a partnership"



"It's important that the team that's working on any of the projects, the providers and clinicians, are also trained to be accepting and non-condescending to a non-clinically trained person"

What were the results?

ICMJE, International Committee of Medical Journal Editors

Guiding principles of the framework



Planning

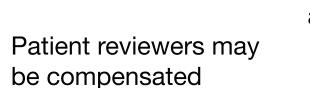
- Identifying and contracting patients may extend timelines
- Planning for patient involvement early is critical for success



criteria

Authorship

 Patient authors will Patient authors must fulfil all four not be compensated ICMJE authorship to avoid the criteria,⁵ in line with perception of bias all other authors





Data privacy

Being named as a patient author in a publication byline may associate that patient with the condition to which the publication relates



guidance can be

applicable across

the enterprise

Guidance and processes included in the framework



Tools to identify the right publications for patient involvement





- Considerations when identifying patient authors or reviewers Language and translation requirements Level of expertise required
- Amount of time commitment required
- Local requirements from relevant country legislation Accessibility, diversity, inclusion and equality



How to identify and contract patient authors or reviewers



- Guidance for identifying patients through:
 - global internal programs
 - consultation with patient advocacy groups or medical societies - external vendors



Detailed guidance for working with patients as authors on publications



- Template emails and documents for initial contact with patients
- Plain language overview of the publication development process for different publication types
- Considerations for journal selection
- Post-publication contact including dissemination plans, process feedback and potential future publications

Framework post-launch metrics



Since its launch in April 2023, the framework has been accessed over 750 times by AstraZeneca employees across the world



The framework has been used to guide patient involvement as authors on



7 conference abstracts, 7 conference presentations and 14 manuscripts

... as reviewers on 9 plain language summaries or plain language summaries of publications

Metrics collected on 12 January 2024. Publication numbers include completed publications as well as those still undergoing drafting.

The processes followed in the development of this framework could be used as a blueprint

for other companies undertaking similar initiatives, thereby increasing the level of patient

How might the framework impact current research and practice?

- The comprehensive guidance provided by the framework will help facilitate meaningful patient involvement as authors and reviewers on AstraZeneca-sponsored publications across global and local markets
- The framework will be continually revised in response to feedback from internal users and patients involved in publications
 - Acknowledgements 5. International Committee of Medical Journal The authors would like to thank the patient ambassadors and AstraZeneca employees who provided feedback to inform the development of the framework. Under the

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Disclosures

involvement in publications across the industry

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