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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 guidelines<sup>1</sup>
  - 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<sup>1,2</sup>
- In light of the value that patients can add, journal editors-in-chief are becoming increasingly accepting of the inclusion of patients as publication authors<sup>3</sup>
- 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 failure<sup>4</sup> 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 recommendations<sup>2</sup> 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 cross-functional team of reviewers

### Process for developing the framework

#### Landscape analysis

##### Peer-reviewed literature

- Structured search of Ovid MEDLINE<sup>®</sup> 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

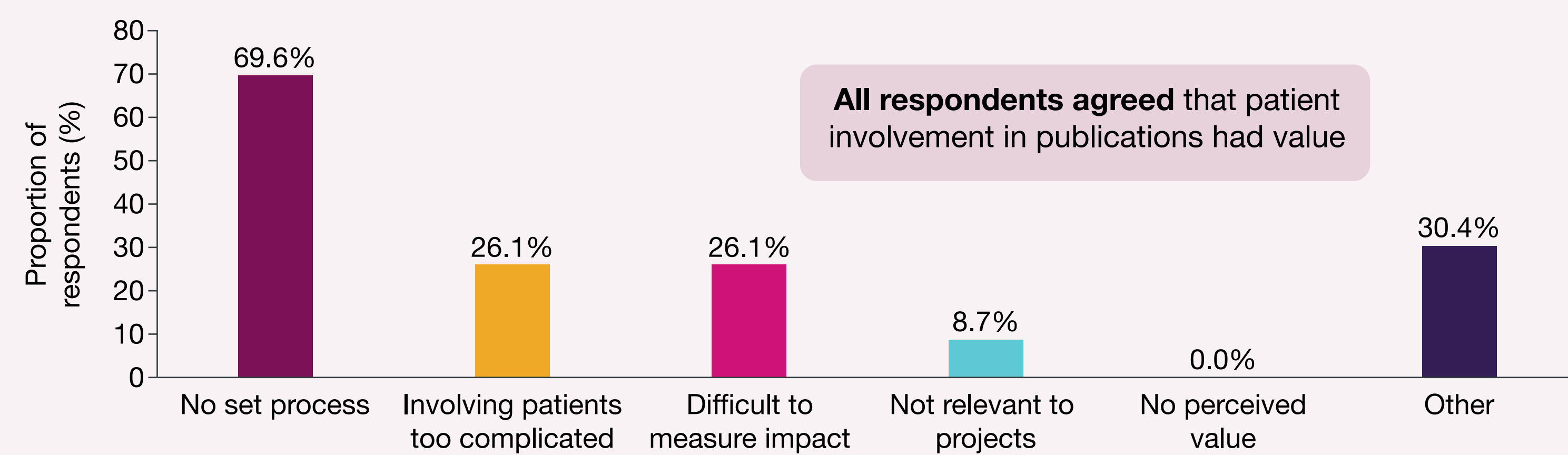
#### Dissemination

##### 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

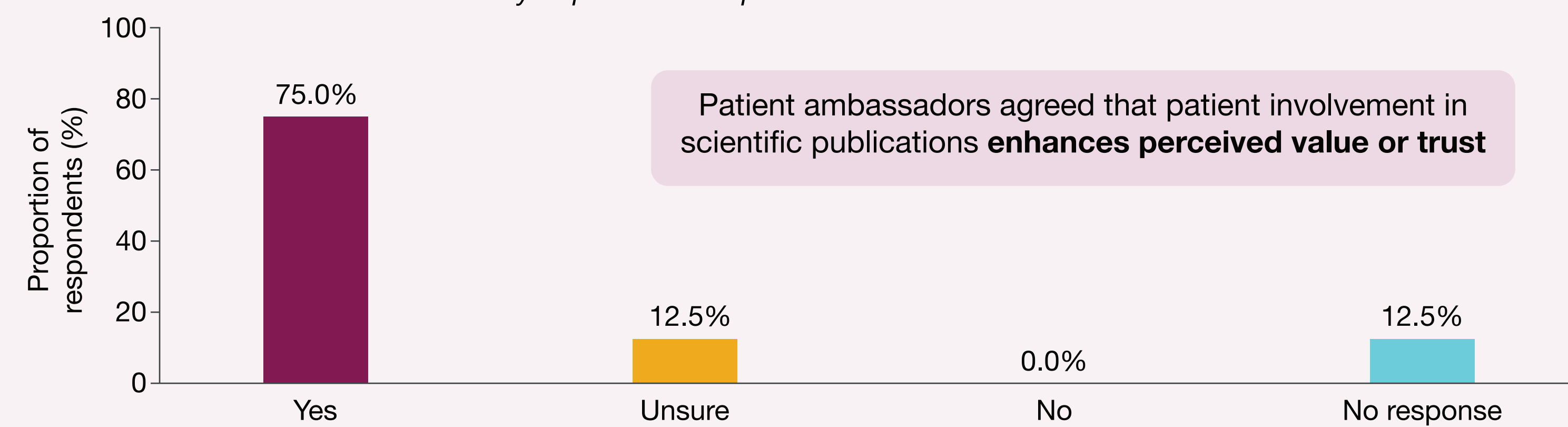


Survey conducted in October 2022. Of 25 individuals surveyed, 23 respondents answered this question in the survey. Question was "In your opinion, what are the current barriers to patient involvement in publications?" Answer was multiple choice where respondents could select multiple options, as well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

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



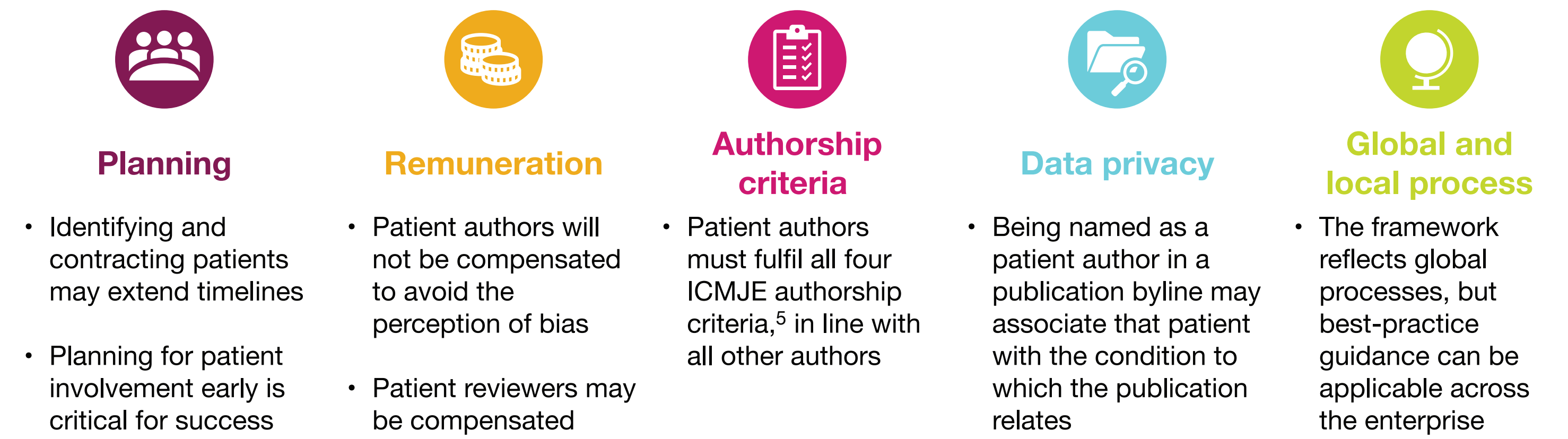
**Poll question:** if you knew that a patient was involved in reviewing or authoring a scientific publication, would that increase the value or trust you place in that publication?



- "Patients trust other patients, so I think it's important that a patient was involved"
- "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"

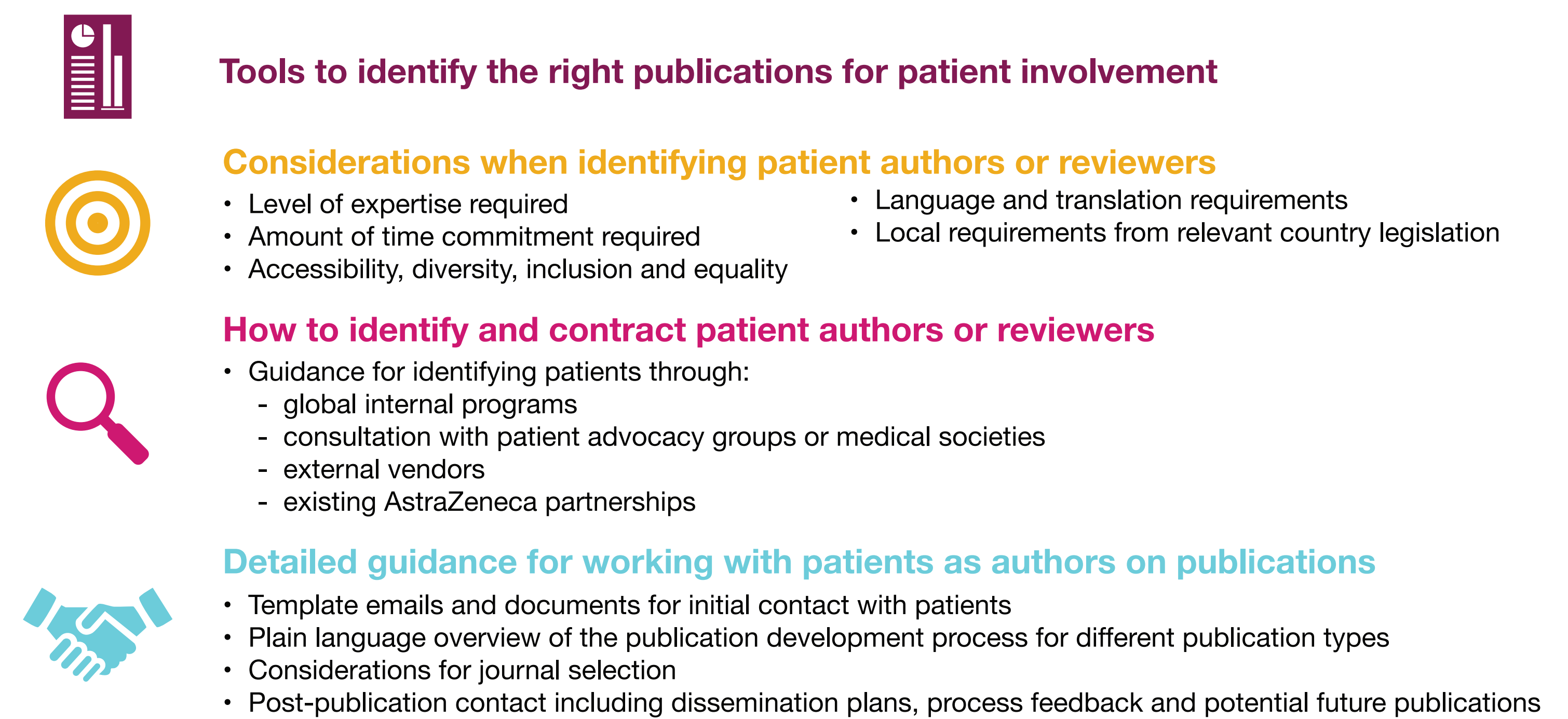
## What were the results?

### Guiding principles of the framework

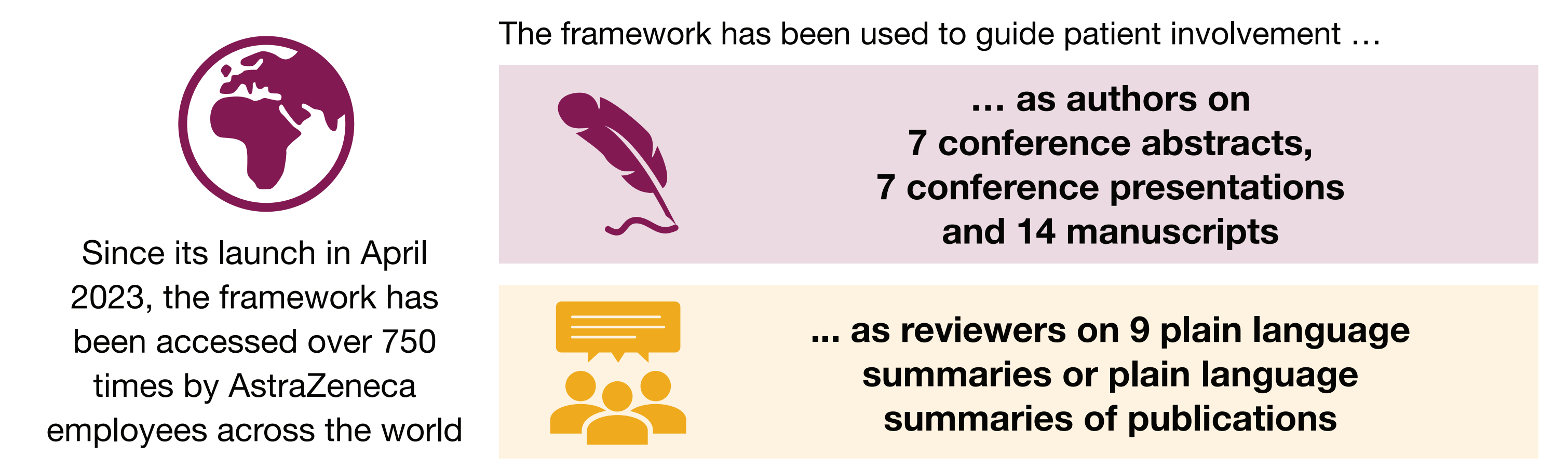


ICMJE, International Committee of Medical Journal Editors

### Guidance and processes included in the framework



### Framework post-launch metrics



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

## 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
- 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 involvement in publications across the industry

## References

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## Disclosures

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