

Poster #22

Guidance for patient engagement in plain language summaries: where are we?

Dawn Lobban,¹ Avishek Pal,² Laura Dormer,³ Sheila Khawaja,⁴ Lauri Arnstein Williams,⁵ Daniela Luzuriaga Ubilla,⁶ and Anne-Marie Hamoir⁷

¹Envision Pharma Group, Wilmslow, UK; ²Novartis Pharma AG, Basel, Switzerland; ³Future Science Group, London, UK; ⁴World Alliance of Pituitary Organizations, Zeeland, The Netherlands; ⁵Envision Pharma Group, London, UK; ⁶Patient Focused Medicines Development, The Synergist, Brussels, Belgium

Background and Objectives:

Guidance for patient engagement in plain language summaries (PLS) of publications is needed¹ and has been initiated by a Patient Focused Medicines Development (PFMD) Working Group (WG)²

We present the co-creation process used to ensure quality and relevance of this guidance to a broad audience

Conclusions:

The multi-stakeholder co-creation process facilitated the development of practical guidance for patient engagement in PLS with broad applicability

The guidance is being updated to incorporate the feedback from Consultation Round 2

The final How-to Guide will be available via the PEM Suite (<https://pemsuite.org/>)

Stages of co-creation to develop the How-to Guide for PLS of peer-reviewed publications and conference presentations

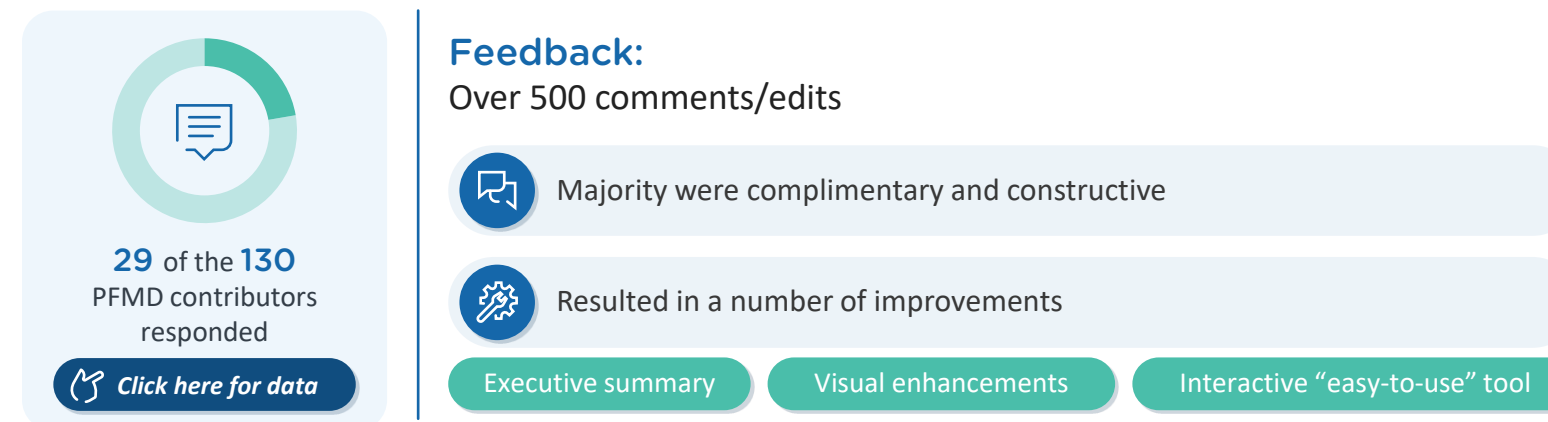
Working Group (WG) Development of Draft

(July 2019 to July 2020)



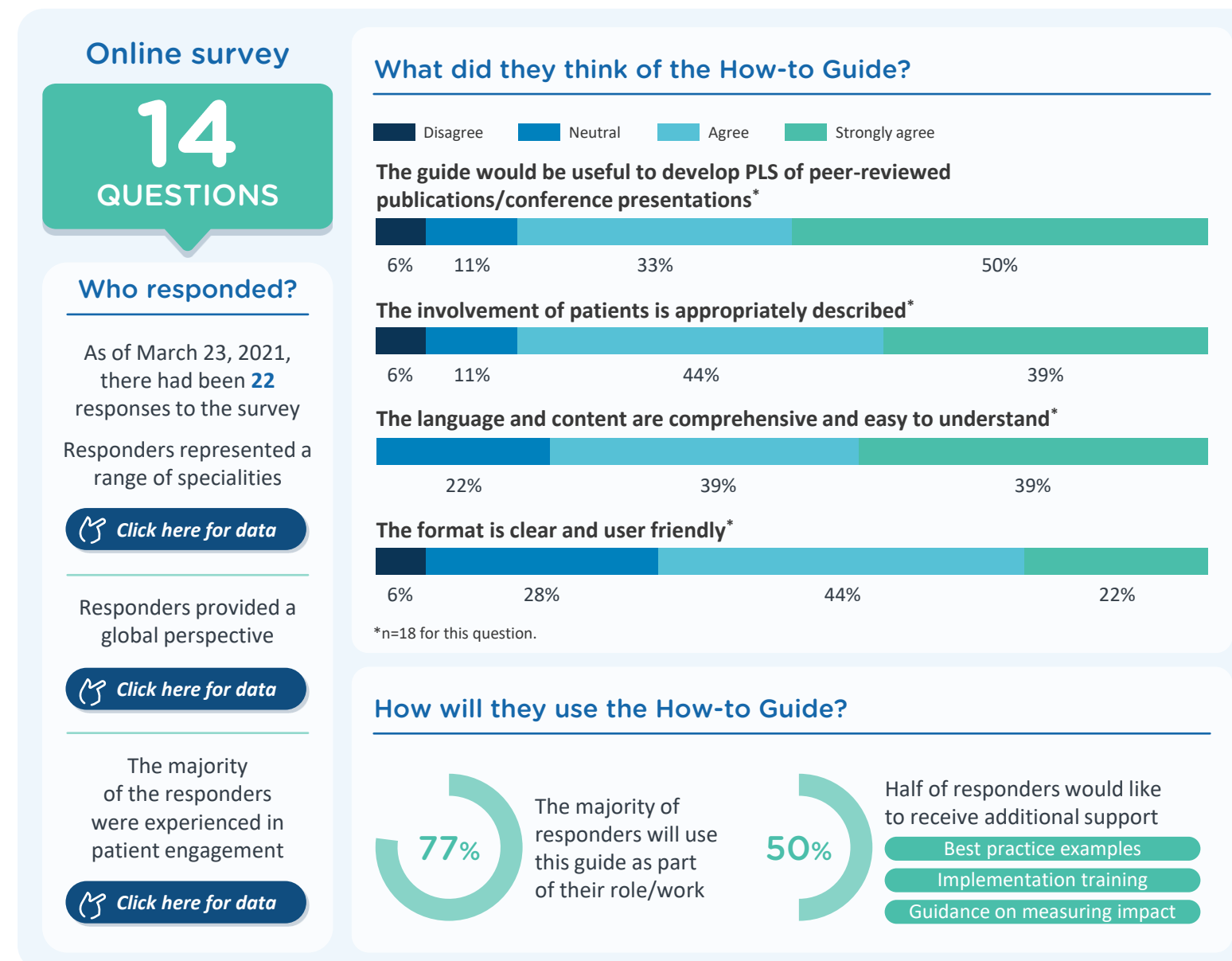
Round 1 - PFMD Contributors

(September 2020 to November 2020)



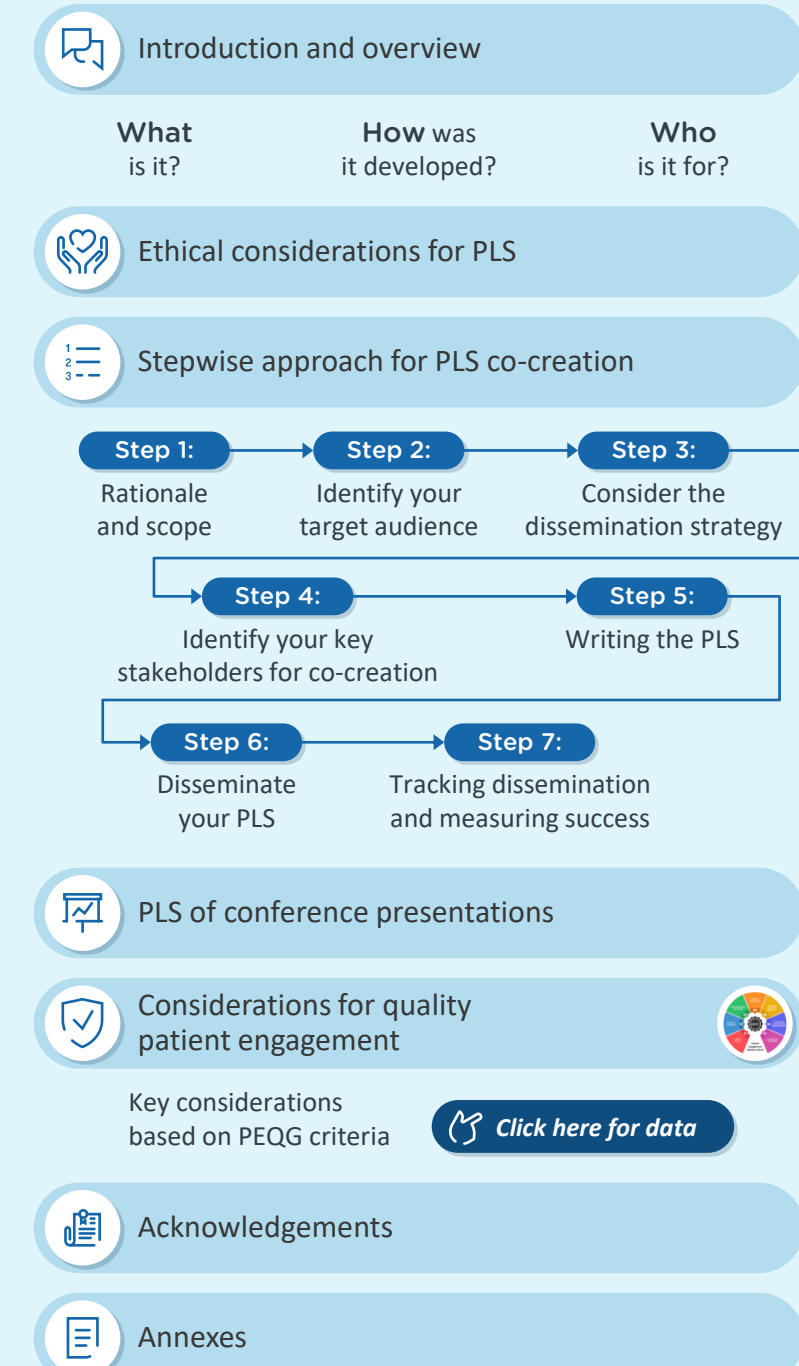
Round 2 - Public Consultation

(February 2021 to April 2021)



Practical How-to Guide for Multi-stakeholder Co-creation

Content overview



Glossary | Resources | Examples | PEQG definitions

To be made available as a PDF and an "easy-to-use" online tool

DISCLOSURES AND ACKNOWLEDGMENTS:

Authors would like to thank all the participants of PFMD Working Group 5 who co-created the draft PLS 'How to' guidance module. We would also like to thank the PFMD contributors and the public who responded to the consultation rounds.
DL, AP, LD SK, and LAW conducted the research in a voluntary capacity. AMH and DLU are employees/consultants of PFMD. All authors were actively involved in development, review, and approval of the poster.

REFERENCES:

- Skovlund SE, et al. Presented at: ISPOR 2019; May 18-22, 2019; New Orleans, LA, USA.
- Khawaja S, et al. Presented at: ISMPP 2020; April 15-17, 2019; National Harbor, MD, USA.

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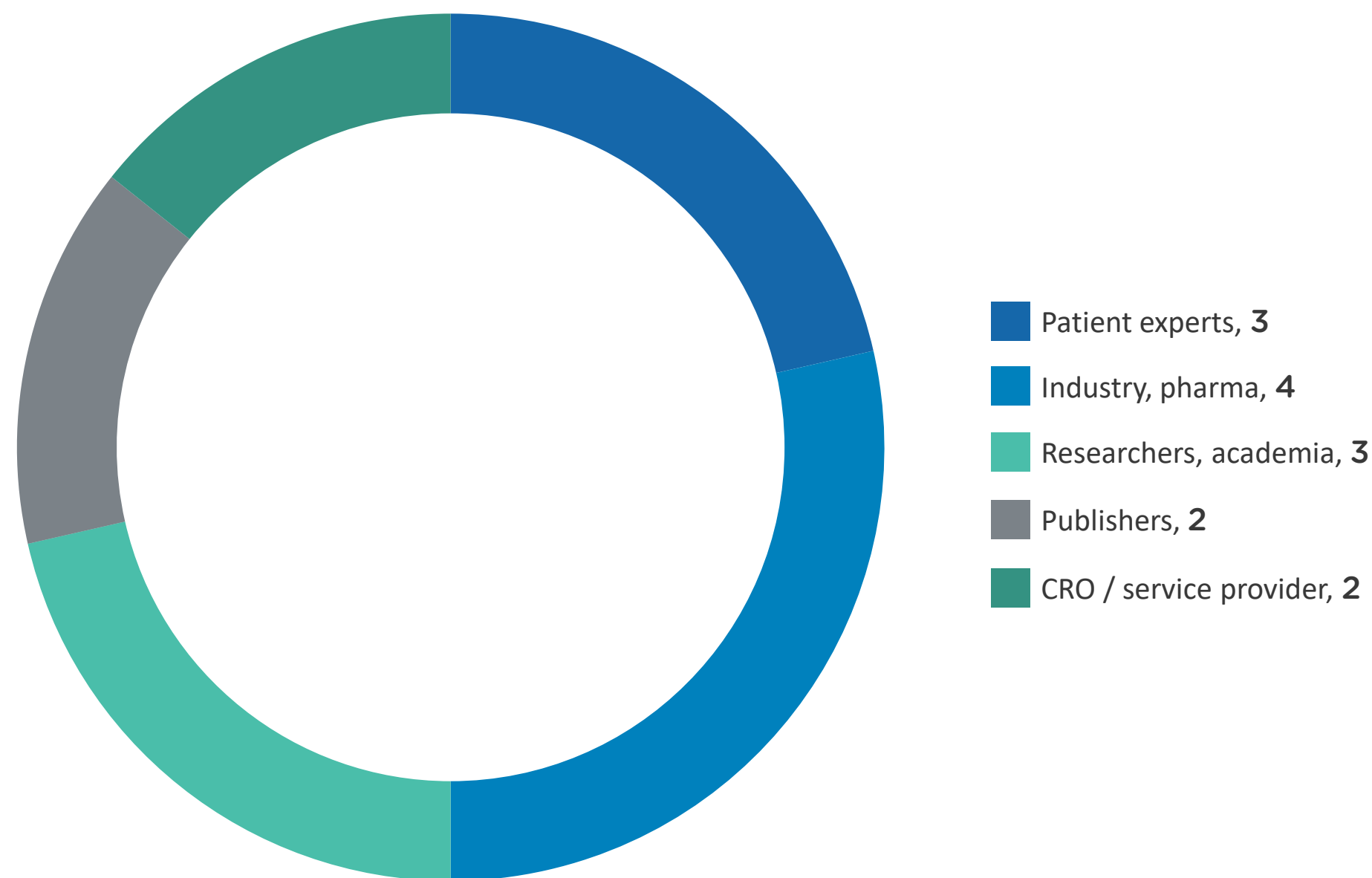
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Stakeholder involvement in co-creation of guidance for patient engagement in PLS

WORKING GROUP

(N=14)



July 2019 – July 2020

patient engagement

77%

responders will use this guide as part of their role/work

50%

Best practice examples

Implementation training

Guidance on measuring impact

Orleans, LA, USA

2. Khawaja S, et al. Presented at: ISMPP 2020, April 15-17, 2019; National Harbor, MD, USA.

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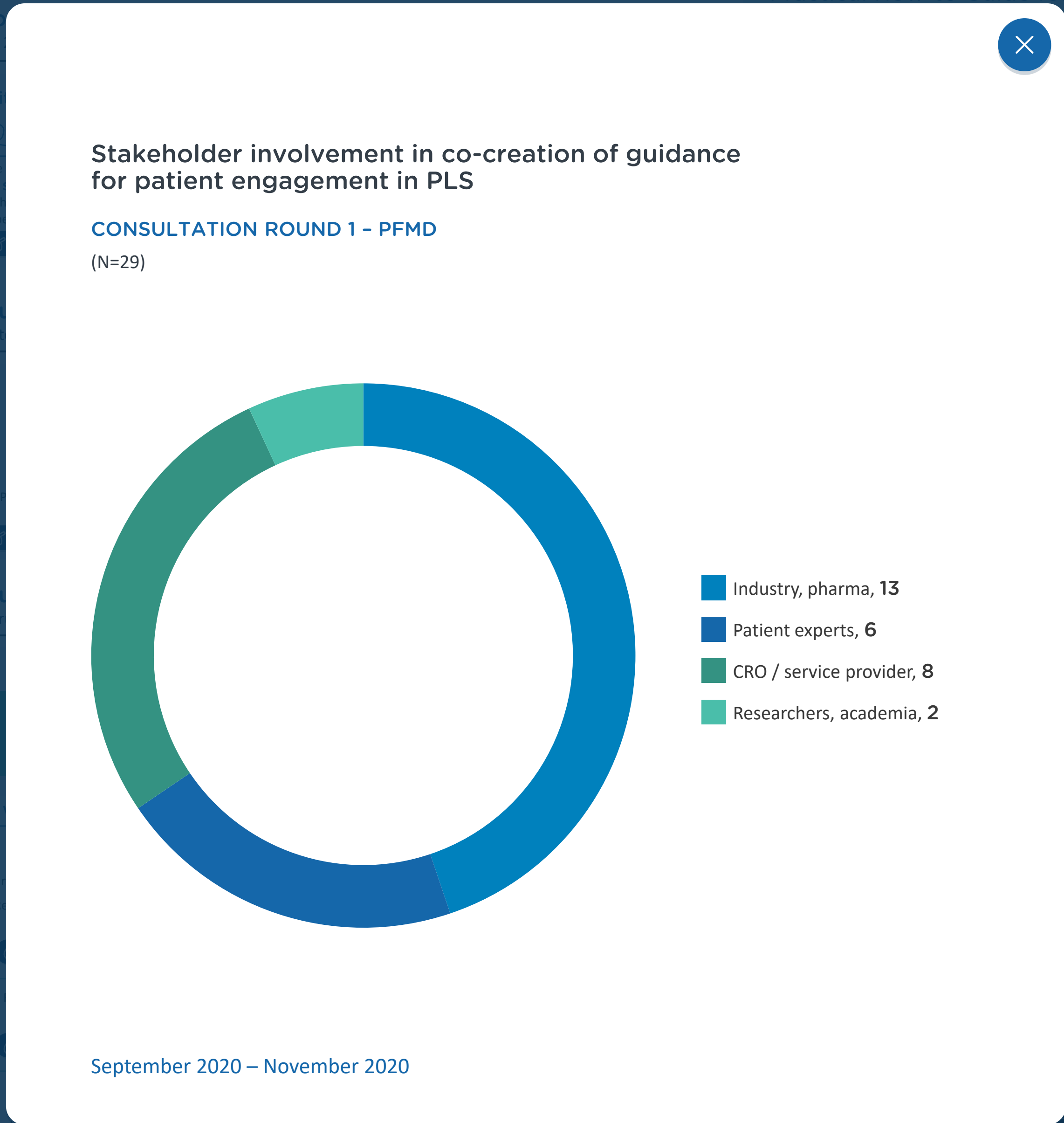
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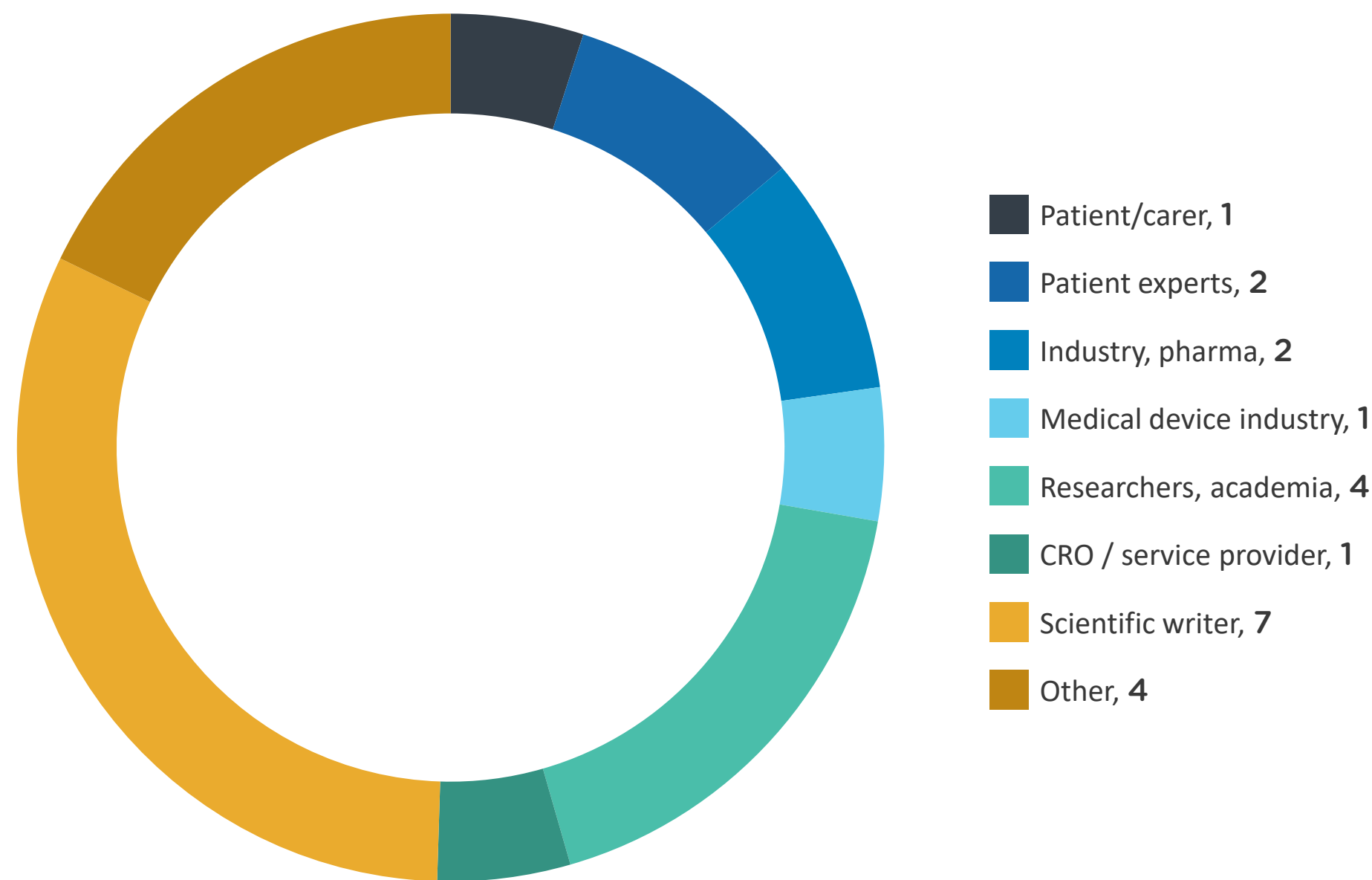
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CONSULTATION ROUND 2 - PUBLIC CONSULTATION

(N=22)



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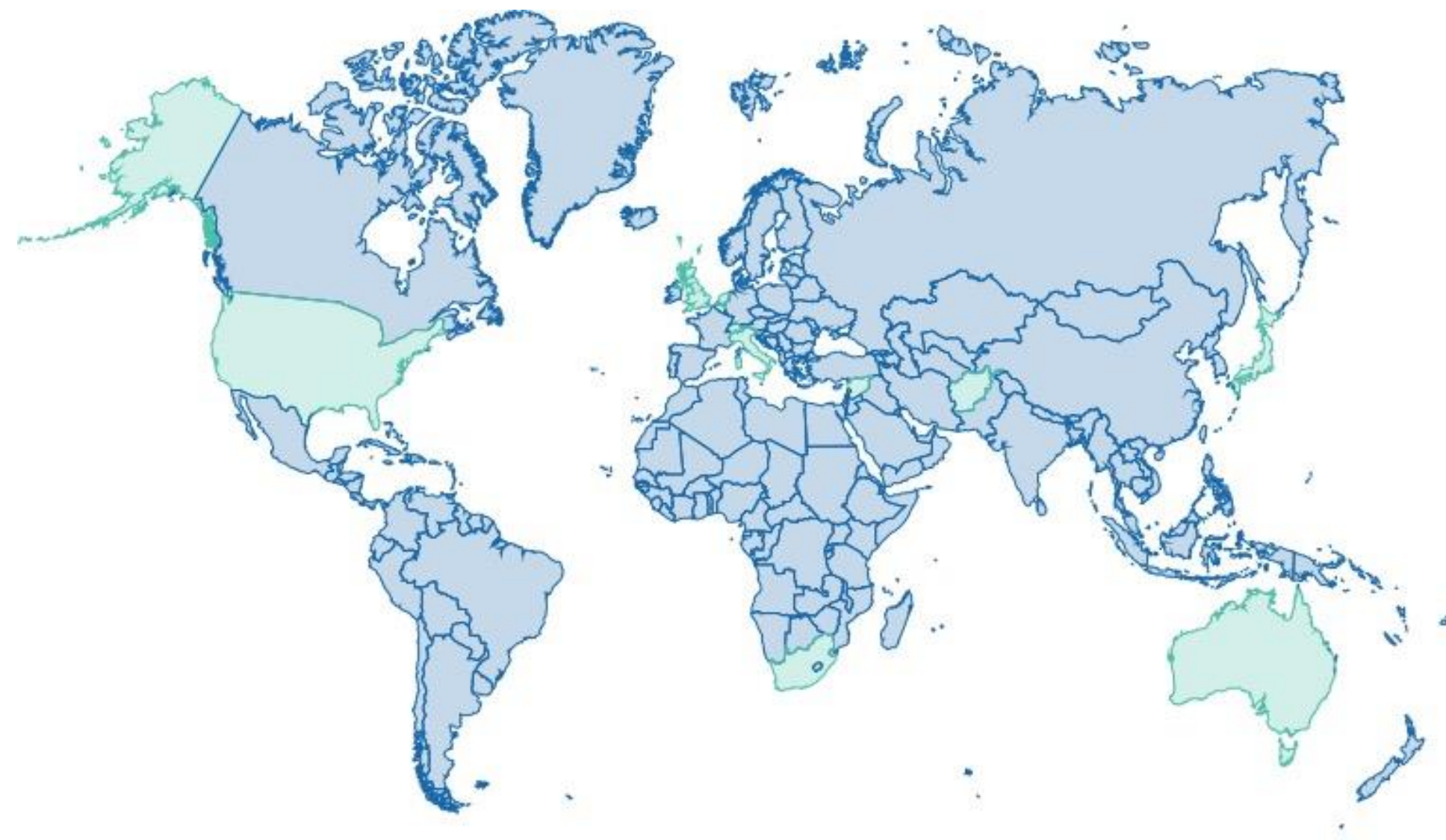
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CONSULTATION ROUND 2 - PUBLIC CONSULTATION

(N=22)



Responders provided a global perspective

- | | | | |
|-------------|-------------|----------------------|----|
| Afghanistan | Italy | South Africa | UK |
| Australia | Japan | Syrian Arab Republic | US |
| Belgium | Netherlands | Switzerland | |

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[Click here for data](#)

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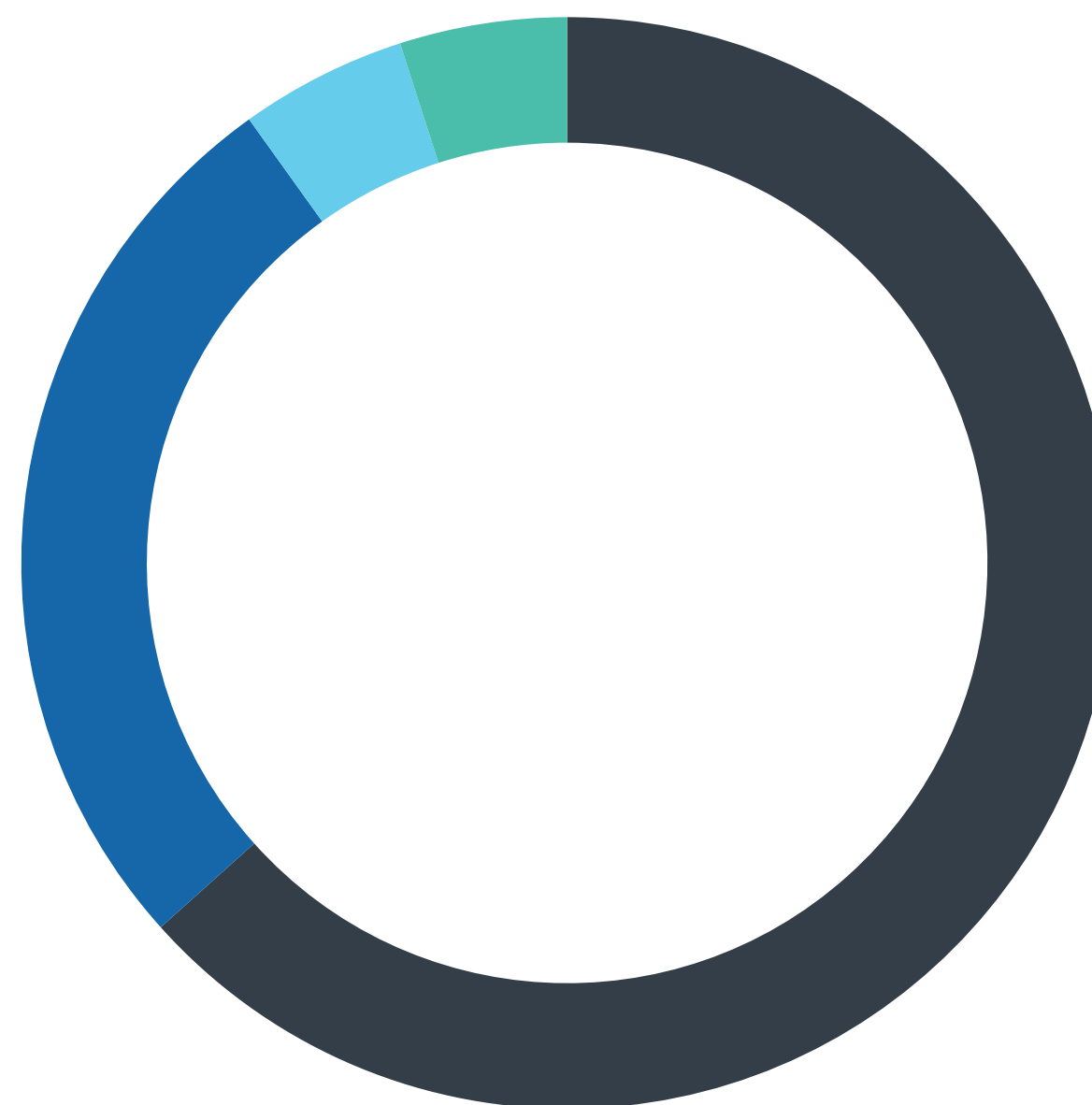


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CONSULTATION ROUND 2 - PUBLIC CONSULTATION

(N=22)



The majority of responders were experienced in patient engagement

- Advanced, 14
- Intermediary, 6
- Beginner, 1
- No experience, 1

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