Are Plain Language Summaries of Health Economic Publications Needed for Patients and Non-expert Audiences?

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Background and Objective

- The importance of patient involvement in outcomes research and in assessing the value of medications is increasingly recognized. [1,2]

- This is further supported by the recent announcement of the ISPOR consensus definition of patient engagement in research[3]

> "The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision-making is guided by patients' contributions as partners, recognizing their specific experiences, values and expertise."
>
> ISPOR definition of patient engagement in research – Harrington et al, 2020[3]

Our research focused on better understanding:

1. Current involvement of patients in health technology assessment (HTA) and health economics and outcomes research (HEOR)

2. Unmet needs and key considerations for plain language summaries (PLS) of health economic publications to support patient involvement in HTA and HEOR

Methods

March 2020
Rapid evidence assessment
- Conducted in accordance with Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) guidelines
- Identified literature (January 2015 to March 2020, English language) on patient involvement in HTA and HEOR

June 2020
Patient expert and health economist interviews
- Interviews among patient experts who had participated in HTA (n=4; Canada, Italy, UK, US) and health economist advisors to HTA (n=2; UK, US/Canada)
- An example PLS was developed for participants to review and consider key PLS criteria

September/October 2020
Plain language "text + visuals" explanation (PLE) development and assessment
- Two PLEs were developed and reviewed by the patient experts and health economists who provided feedback on the PLS examples
- Additional feedback is being collected to optimize the PLEs. Additional relevant PLEs may be developed for inclusion in the HTA/HEOR PLS toolkit

2021
Plain language toolkit for HTA/HEOR PLS
- Further research is planned to develop and test an HTA/HEOR PLS toolkit and identify approaches to better integrate PLS within HTA and HEOR frameworks

Results

Rapid evidence assessment (REA)

50 (80.6%)
evaluated the role of patients in HTA

62 publications were included in the REA

12 (19.4%)
focused on patient involvement in HEOR studies

- Across the identified publications, patient involvement in HTA and HEOR was considered important; however, significant challenges were identified, including communicating the purpose of HTA and HEOR, methodologies, and technical data to patient partners[4]

Interviews

- Patient and health economist interview participants strongly supported patient involvement in HTA and HEOR, but highlighted similar challenges[4]
- Both the REA and interviews indicated that consistent use of PLS could help to facilitate patient contributions to HTA and HEOR by addressing communication challenges and creating equity with respect to other stakeholders
- In addition to patient-accessible language, using infographics and interpreting study data from the patient perspective were noted as important considerations for PLS

> "It levels the playing field, and puts everyone on an equal footing so patients can speak with authority on what they have read. Levelling the playing field is crucial in this activity."
>
> Patient quote on the potential benefits of PLS in HEOR/HTA

PLE: survey results

- Preliminary testing of the cost-effectiveness "text + visuals" PLE highlighted the need to not only provide clarity around technical terminology but also provide context on the purpose and utility of evaluating cost-effectiveness for healthcare decision-making
- The accompanying PLE "What is HTA?" was developed to help address this need. Continued testing of both PLEs is ongoing

What next?

- Development of an HTA/HEOR plain language toolkit is ongoing, aligned with and augmenting an existing resource for PLS of peer-reviewed publications and congress abstracts[5]
- Further research is also required to identify approaches to better integrate PLS within HTA and HEOR frameworks

Limitations

- This study represents preliminary research among a small sample of interviewees and survey respondents; further research is required to validate the findings
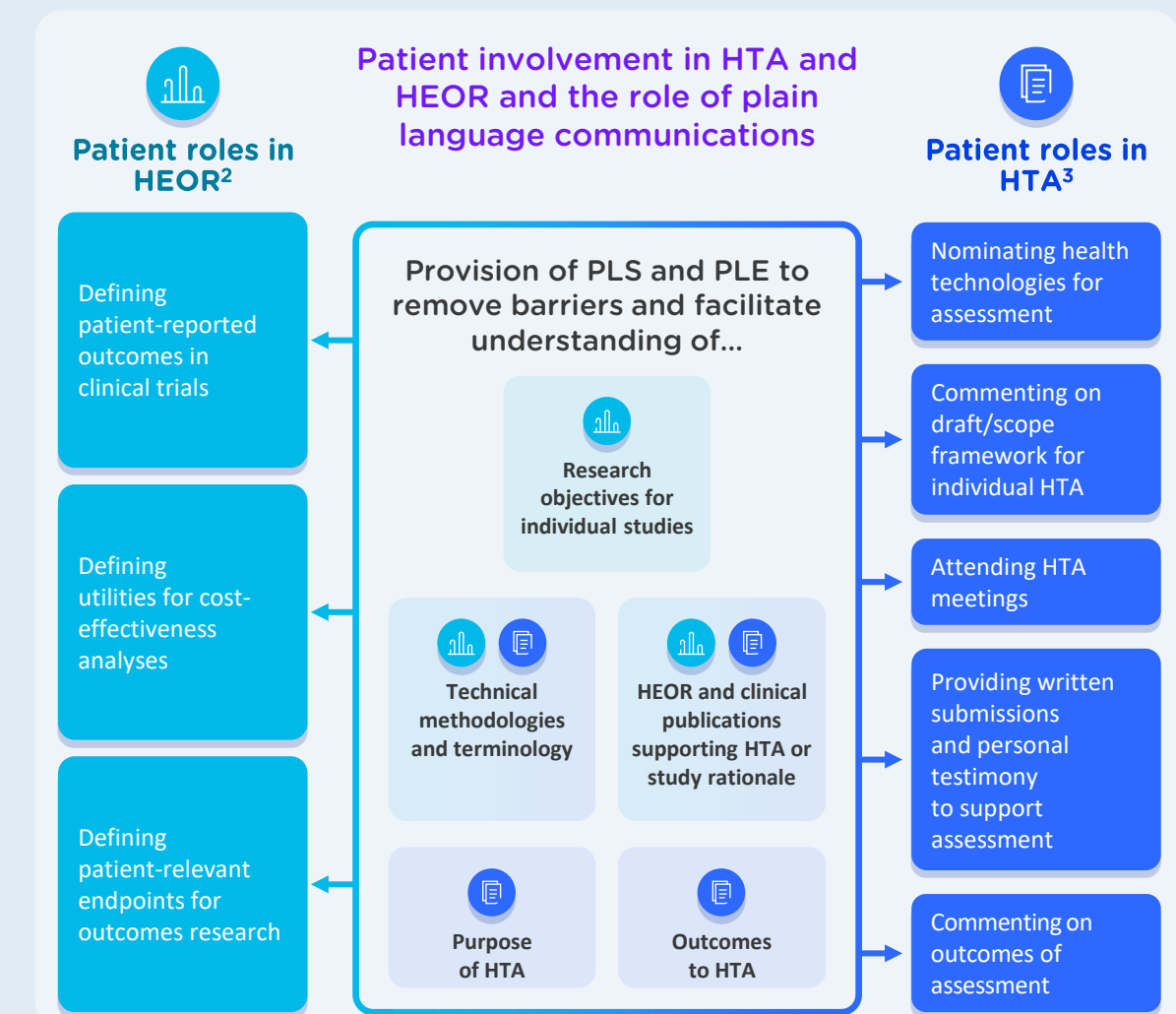
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1. Ung B, Khan Z, Willke R, et al. *Value & Outcomes Spotlight.* 2019;5(1):31-33. **2.** Hunter A, Facey F, Thomas V, et al. *Front Med (Lausanne).* 2018;5:231. **3.** Harrington R, Hanna ML, Oehrlein EM, et al. *Value Health.* 2020;23(6):677-688. **4.** Harvey E, Blumer Z, Carthy J, et al. *Value Health.* 2020;23(Suppl 2):S683. **5.** Envision Pharma Group. Plain Language Summaries (PLS) of Publications Toolkit. URL: https://www.envisionthepatient.com/plstoolkit/. Accessed November 5, 2020.

Conclusions

There is a need for consistent use of plain language communications to support patient involvement in HTA and HEOR

Our research identified several areas where the use of plain language communications of both health economic and other publications could remove barriers and help to facilitate patient involvement in HEOR and HTA

Patient involvement in HTA and HEOR and the role of plain language communications

Patient roles in HEOR[2]
- Defining patient-reported outcomes in clinical trials
- Defining utilities for cost-effectiveness analyses
- Defining patient-relevant endpoints for outcomes research

Provision of PLS and PLE to remove barriers and facilitate understanding of...
- Research objectives for individual studies
- Technical methodologies and terminology
- HEOR and clinical publications supporting HTA or study rationale
- Purpose of HTA
- Outcomes to HTA

Patient roles in HTA[3]
- Nominating health technologies for assessment
- Commenting on draft/scope framework for individual HTA
- Attending HTA meetings
- Providing written submissions and personal testimony to support assessment
- Commenting on outcomes of assessment

What are plain language communications?

Any form of communication intended to convey technical information to a non technical audience, particularly patients

In developing a plain language toolkit for HEOR and HTA, we are developing 2 forms of plain language communications:

- **PLS:** Brief "text + visuals" summaries of publications or individual studies.
- **PLE:** Brief "text + visuals" explanations of technical methodologies or processes.

Access the QR codes or click the links below to view examples of 2 PLEs

What is HTA?
https://bit.ly/3oPPmN7

How do we assess cost-effectiveness?
https://bit.ly/360Qftt

Once you've reviewed the PLE examples, contribute to our continued research on the format and effectiveness of PLEs by taking our survey, linked below

https://www.surveymonkey.co.uk/r/MJMTLB6