

# DEFINITIONS FOR PATIENT ENGAGEMENT AND CENTEREDNESS IN HEALTH CARE RESEARCH AND PRACTICE: A SYSTEMATIC REVIEW BY THE ISPOR PATIENT CENTERED SPECIAL INTEREST GROUP

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## BACKGROUND

- The ISPOR Patient Engagement in Research Working Group was formed in April of 2014 to identify best practices for involving patients and their representatives in research.
- While doing so, the group deemed it imperative to arrive at a recommended standard term and definition for "patient engagement" and "patient centeredness" to be used in ISPOR communications and publications.

## OBJECTIVES

- Identify existing definitions in published and grey literature for "patient engagement," "patient centeredness," and related terms, especially in the context of research, drug development, and health care decision making.
- Extract common themes from definitions to guide development of an ISPOR definition for "patient engagement" and "patient centeredness."

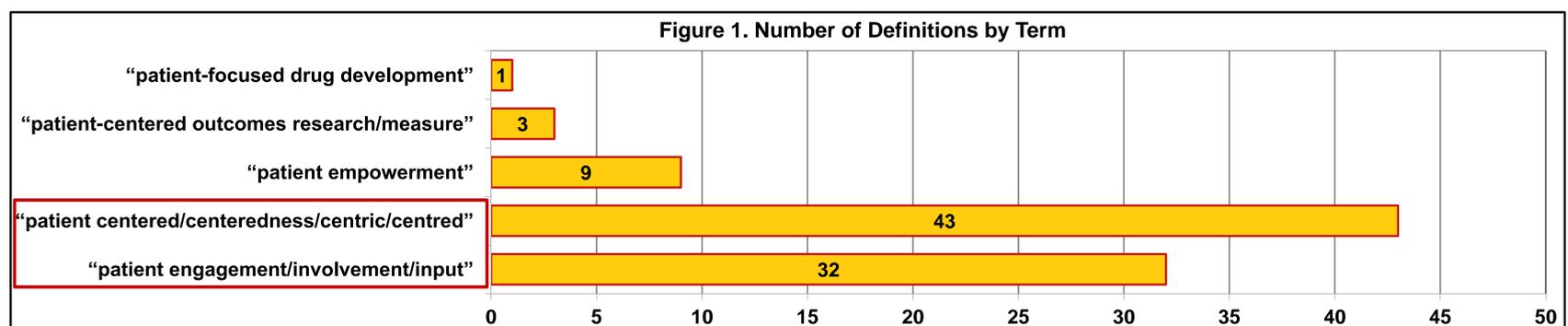
## METHODS

The following search strategy was used:

- Inclusion criteria established *a priori* for both searches required a definition for "patient centeredness", "patient engagement", or a related pre-specified term; and the definition was to be associated with health care research and/or provision, and in English language.
- Published literature:** Consisted of a PubMed and EMBASE database search for definitions in available literature from inception through October 18, 2015.
  - PUBMED- (patient engagement[Title/Abstract] OR consumer engagement[Title/Abstract] OR patient involvement[Title/Abstract] OR patient cent\*[Title/Abstract] OR consumer cent\*[Title/Abstract] OR person cent\*[Title/Abstract] AND definition[Title/Abstract] OR "defined as"[Title/Abstract])
  - EMBASE- ('patient centered outcomes research' OR 'patient engagement' OR 'patient involvement' OR 'person centered care' AND 'definition' OR 'defined as')
  - Abstracts were screened for relevance by two researchers independently, followed by a full text review to extract the definitions. Any disagreements were resolved by consensus. A third researcher was brought in to resolve any remaining discrepancies.
- Grey literature:** Consisted of searches among public and private domains worldwide.
  - Experts and patient advocates were consulted to identify domains such as "umbrella" patient advocacy organizations and other organizations considered prominent in the field of patient engagement and centeredness.
  - A Google site operator was employed to identify additional definitions in grey literature.
  - Results were assessed by two researchers for relevance. Any disagreements were resolved by consensus. A third researcher was brought in to resolve any remaining discrepancies.
- Definitions for "patient engagement" and "patient centeredness" were further summarized and analyzed using a non-quantitative, meta-narrative approach.

## RESULTS

- 371 published articles and 164 government and non-governmental organizational websites were reviewed for use of terms and definitions.
- 88 definitions were identified. (Figure 1)
- 17 unique definitions for "patient engagement" resulted in 8 themes. (Figure 2)
- 28 unique definitions for "patient centeredness" resulted in 8 themes. (Figure 3)



**Figure 2. Themes from "patient engagement" definitions**



**Figure 3. Themes from "patient centeredness" definitions**



## DISCUSSION

- Patient's voice* and *patient/provider partnerships* overlapped as important themes for "patient engagement" and "patient centeredness".
- Sources came from United States, Canada, Europe, England, Australia, Mexico, and New Zealand.
- Contexts included patient care, research, informed consent, cost, health literacy, shared decision making, and health services delivery.
- Additional terms were found for "patient engagement" and "patient centeredness" not considered *a priori*, such as "patient involvement", "patient input", and "patient oriented".
- Publication results of this pilot study were deemed insufficient, as articles known to include relevant definitions were not captured in the aforementioned search strategy.
- Thus, the literature-based search needed to be modified to a more exhaustive search, including an expanded list of related terms, the addition of Medical Subject Headings (MeSH) terms: [Patient Participation] and [Patient-Centered Care], and limiting the publication dates from 2006 [data not shown].

## CONCLUSIONS

- The Institute of Medicine, Patient Centered Outcomes Research Institute and many other stakeholders in the health care community have established definitions for "patient engagement" and "patient centeredness".
- These definitions serve as a foundation for the Patient Engagement in Research Working Group as it examines these themes and guides consensus on ISPOR's standards for terms.
- Future work will address completing the enhanced literature search that resulted, updating the themes, stratifying definitions by research versus healthcare, and further validating themes with experts.

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