ATTRIBUTES DEFINING PATIENT ENGAGEMENT AND CENTEREDNESS IN HEALTH CARE RESEARCH AND PRACTICE: A FRAMEWORK DEVELOPED 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.
- Present preliminary results based on an expanded search of patient terms.
- 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 (figure 2); 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 January 1, 2006 to March 31, 2016.
  - 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.
    - Inclusion Criteria: Definition of term is in abstract; Purpose/Objective of the paper is to define term or introduce, examine, or analyze a conceptual model/framework; Systematic Review of term definition or concept; Opinion paper on term about its use or importance in health care/research; Unclear for Inclusion or Exclusion without full-text review
    - Exclusion Criteria: No Patient Terms Defined OR framework referenced; Not Health Care/Research Related ; Term used to describe a treatment approach/intervention in a specified population (i.e. colorectal surgery or TBI rehabilitation) without indication of defining term; Term used in context of improved communications or infrastructure of an organization through information technology (i.e. patient portals, electronic health records (EHRs, devices, equipment, web-based tools, etc.) without indication of defining term
- ***Full-text Review and Data Extraction:***
  - Researchers and patient representatives reviewed full-text articles for patient-related terms and their definitions. They identified if the definition was adapted or adopted from another reference or source or if the article authors provided their own original definition. Reviewers recorded the context the definitions were used in such as healthcare delivery, research, both or other. If the article provided a framework for composition of the definition, this was also recorded.
  - Preliminary descriptive results were summarized and analyzed.

RESULTS

1765 abstracts were screened for relevance resulting in 514 full-text articles reviewed for “patient” term definitions.

Figure 1. “Patient” term definition results

187** Definitions were extracted

Patient Focused (3)
Patient Focused Drug Development (1)
Patient Focused Outcomes Research (2)
Patient Centered** Outcomes Research (5)
Patient Centered/Centric/Centeredness (80)
Consumer Centered/Centric/Centeredness (0)
Person/People Centered/Centric/Centeredness (7)
Patient Engagement (28)
Consumer Engagement (limit to health care) (1)
Patient Empowerment (14)
Patient Involvement (20)
Consumer Involvement (0)
Patient Input (1)
Patient Oriented (1)
Patient Participation (24)

*EU spellings of any terms were also searched. i.e. ‘centred’
** Preliminary findings

Figure 2. Key words from “patient engagement” definitions

Includes the following terms:

- Patient Engagement
- Consumer Engagement (limit to health care)
- Patient Empowerment
- Patient Involvement
- Consumer Involvement
- Patient Input
- Patient Participation

Figure 3. Keywords from “patient-centered” definitions

Includes the following terms:

- Patient Focused
- Patient Focused Drug Development
- Patient Focused Outcomes Research
- Patient Centered/Centric/Centeredness
- Patient Centered Outcomes Research
- Patient Centered Drug Development
- Consumer Centered/Centric/Centeredne
- Person Centered/Centric/Centeredness
- Patient Oriented

Table 1. Select Patient Engagement Themes by Context

Health Care System / Structure / Delivery
− Incorporating values, experiences, perspectives in design and governance of health care system
− Active influence in the provision of medical care
Patient / Provider Behavior
− Shared decision making/deliberation/mutual agreement
− Patients who are information seeking and demonstrating assertiveness
− Clinician respects patients own decision; patients 'voice' is heard
− Patients as expert partners; human capital
− Patient takes control of life and management of disease/health
Health-related Research
− Identifies gaps in research
− Study recruitment and data collection
− Maximize success and translation of research
− Involved/part of health care policy and quality research

Table 2. Select Patient-centered Themes by Context

Health Care System / Structure / Delivery
− Involvement in service planning and evaluation
− Care that 'measures up' to patient needs and values
− The right care, to right patient, at right time
Patient / Provider Behavior
− Clinician respects/responsive to patient needs/preferences/desires/values/goals
− Patients involved in health care planning / therapeutic alliance
− Patient seen as unique human beings/ person rather than disease/ dignity
− Patients as expert partners; human capital
Health-related Research
− Develop/validate patient-reported outcome assessments
− Endpoints and outcomes meaningful to patients
− End users of benefit-risk framework
− Members of clinical research advisory committee
− Active/relevant community beyond researchers

DISCUSSION

- This is a *preliminary* analysis of data abstracted to date. More in-depth analysis of patient term attributes are need with input from the ISPOR community.
- A multitude of articles mentioning terms were identified; however, a more limited number of definitions were identified.
- Although some definitions are lack relevancy and are outdated, a number of themes are converging to help us get to standard definitions.

CONCLUSIONS

- Many stakeholders in the health care community use “patient” terms to describe an approach towards improved healthcare delivery and drug/clinical research.
- Definitions for “patient engagement” and “patient centeredness” vary and require harmonization.
- 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 involve finalizing data abstraction and finalize the qualitative analysis.
- Themes will be further discussed with the broader ISPOR community and undergo validation with relevant stakeholders.

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