

# WHAT DO WE MEAN BY PATIENT ENGAGEMENT? A QUALITATIVE CONTENT ANALYSIS OF CURRENT DEFINITIONS

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## Background

- Lack of clarity on the definition of “patient engagement” has been highlighted as a barrier to fully implementing engagement in research.<sup>1,2</sup>
- Heterogeneity among existing definitions may lead to inappropriate and/or interchangeable use.<sup>3,4</sup>
- Identifying attributes of specific terms and their context can inform a consensus definition.

## Objectives

- To identify relevant attributes of definitions of patient engagement, patient centeredness, and related terms.
- To identify and analyze themes associated with definitions of patient engagement, compared to other terms.
- To identify and analyze themes associated with the research setting, compared to other settings of activities, such as healthcare.

## Methods

### Data source:

- Systematic review of the English-language literature, 2006 through 2016 (methods and results previously reported)<sup>5</sup>
- Defined terms and associated definitions extracted based on consensus by abstraction team (pairs)

### Qualitative Content Analysis:

- Iterative, inductive approach to coding, describing and analyzing themes<sup>6</sup> (Figure 1)
- Standardized coding dictionary derived from microanalysis and pilot testing, with codes defined in five theme categories (Figure 2)
- Six reviewers (RC, MH, RH, FN, AS, RW), working in pairs, reviewed and coded each definition – third reviewer as tiebreaker

### Statistical Analysis:

- Descriptive analyses, with frequency and relative ranks of coded concepts examined overall, by term, and by coding categories
- Coding conducted in Microsoft Excel (2013), analysis conducted in Excel and SAS 9.4

Figure 1: Qualitative Content Analysis Process

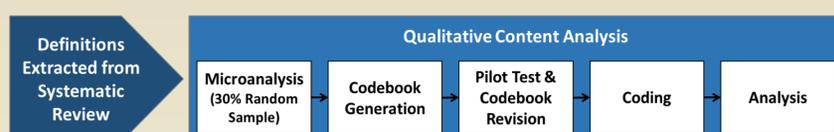


Figure 2: Coding Categories



## Results

- A total of 239 definitions were assessed, contributed by 167 unique articles
- Most frequently defined terms: “Patient Centered” (30.5%), “Patient Engagement” (15.5%), and “Patient Participation” (13.4%)

Table 1: Top 10 Coded Themes (Characteristics), by Defined Term

Rank	Overall (n = 239)	Patient Engagement (n = 37)	Patient Centered (n = 106)	Other (n = 133)
1	patient as participant	process: active	incorporate patient: preferences	patient as participant
2	patient involvement	patient involvement	incorporate patient: perspective	patient in control
3	incorporate patient: preferences	patient as participant	relationship: patient-provider	decision-making: shared
4	relationship: patient-provider	decision-making: shared	<u>individualized approach: care</u>	<u>information sharing</u>
5	decision-making: shared	<u>engagement</u>	<u>understanding</u>	patient involvement
6	patient as partner	<u>set of behaviors</u>	<u>patient as person</u>	process: active
7	incorporate patient: perspective	incorporate patient	<u>holistic approach to patient</u>	<u>empowerment</u>
8	process: active	incorporate patient: preferences	patient as partner	patient as partner
9	individualized approach: care	patient as partner	decision-making: shared	relationship: patient-provider
10	information sharing	relationship: patient-provider	patient as participant	<u>autonomy</u>

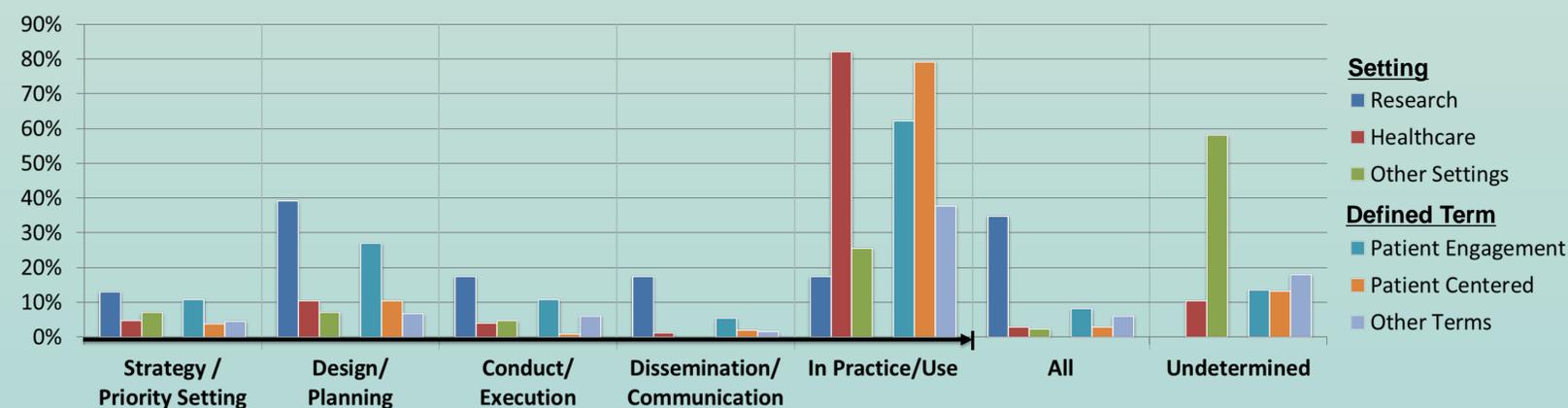
Patient Centered includes the terms: Patient Centered, (n=73) \*Centeredness (n=19), \*Centric (n=3) and Person Centered (n=11)

Other includes the terms: Patient Involvement (n=27), Patient Participation (n=32), Patient Empowerment (n=29), Patient Focused (n=4), Consumer Involvement (n=2), Patient Input (n=1), Patient Oriented (n=1)

Underline indicates themes unique to “top 10” of that particular term

- The most frequent Setting of Activity was Healthcare (72.4%), followed by Other (18.0%) and Research (9.6%)
- The most frequent themes, by Setting, were:
  - Healthcare: “relationship: patient-provider”, “patient as participant”, “incorporate patient: preferences”
  - Research: “patient involvement”, “patient as partner” and “collaboration”
  - Other Settings: “decision-making: shared”, “patient in control” and “patient as partner”
- The most frequent Stages of Activity were “In Practice/Care” (65.7%) and “Design/Planning” (12.6%)
- “Research” had the highest proportion of engagement across “all stages” (34.8%) among the different setting

Figure 3: Defined Involvement Across Stages of Activity, by Setting and Term



## Conclusions

- Though overlap exists, themes associated with the term “Patient Engagement” and a setting of “Research” differ from those of similar terms, confirming that interchangeable use is inappropriate.
- Results are limited by the focused scope of the systematic review on the published literature. Next steps should consider alignment with grey literature, including patient organization-generated definitions.
- Findings from this study provide an opportunity to move forward towards a focused definition of patient engagement in research.

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