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ISPOR Report

Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group



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ABSTRACT

Objectives: Lack of clarity on the definition of “patient engagement” has been highlighted as a barrier to fully implementing patient engagement in research. This study identified themes within existing definitions related to patient engagement and proposes a consensus definition of “patient engagement in research.”

Methods: A systematic review was conducted to identify definitions of patient engagement and related terms in published literature (2006–2018). Definitions were extracted and qualitatively analyzed to identify themes and characteristics. A multistakeholder approach, including academia, industry, and patient representation, was taken at all stages. A proposed definition is offered based on a synthesis of the findings.

Results: Of 1821 abstracts identified and screened for eligibility, 317 were selected for full-text review. Of these, 169 articles met inclusion criteria, from which 244 distinct definitions were extracted for analysis. The most frequently defined terms were: “patient-centered” (30.5%), “patient engagement” (15.5%), and “patient participation” (13.4%). The majority of definitions were specific to the healthcare delivery setting (70.5%); 11.9% were specific to research. Among the definitions of “patient engagement,” the most common themes were “active process,” “patient involvement,” and “patient as participant.” In the research setting, the top themes were “patient as partner,” “patient involvement,” and “active process”; these did not appear in the top 3 themes of nonresearch definitions.

Conclusion: Distinct themes are associated with the term “patient engagement” and with engagement in the “research” setting. Based on an analysis of existing literature and review by patient, industry, and academic stakeholders, we propose a scalable consensus definition of “patient engagement in research.”

Keywords: definition, health economics, outcomes research, patient centered, patient centric, patient engagement, patient research.

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Introduction

Over the past few decades, the concepts of “patient engagement” and “patient-centeredness” have risen to prominence across the healthcare ecosystem.¹ Rather than serving merely as research subjects, the patient community increasingly has the capacity to partner or lead in research.² At a systems level, meaningful involvement of patients and increased understanding of patient experiences, goals, and needs through partnerships in the research process leads to more relevant and effective research.³ Better understanding and incorporation of patient

perspectives through early and continuous partnerships has the potential to enhance the impact of research. This, in turn, results in better, more patient-relevant outcomes because of easier recruitment, retention of study participants, and improved interpretation, which may contribute to faster and broader access to new and better treatment options.^{4,5} At an individual level, data that are generated with patient engagement can ensure the availability of patient-relevant information, enhancing active patient participation in their healthcare decision making.⁶

The role of patients as partners in health technology development has increased over the past decade, driven by the

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expectation of regulatory bodies, health technology assessment (HTA) authorities, and patients themselves that patients' needs and priorities be understood.^{7–10} This patients-as-partners model has also been taken up by industry and others in the recognition that it can lead to better decisions and outcomes, more efficient processes, improved patient recruitment and participation, and shorter lead times.⁷ These developments are reflected in the adoption of laws and policies related to patient-focused drug development in both the United States and the European Union; changes to regulatory standards on clinical outcome assessments; and the growing global impact of patient advocates and citizen scientists on regulatory decision making.^{11–16} These efforts are complementary to the growing role of patient engagement and centrality in healthcare research and delivery. Research organizations have begun to incorporate patients across all levels of decision making, including agenda setting, project planning, implementation, and evaluation.¹⁷ In the United States, this has been influenced by the establishment of the Patient-Centered Outcomes Research Institute, the Agency for Healthcare Research and Quality, and healthcare quality efforts.^{18,19} In Europe, this has been reflected in the work of organizations, such as the European Patients' Academy and the European Organization for Rare Diseases, to champion the empowerment of patients to participate as leaders, partners, and decision makers in the development of health technologies.^{20,21} Active efforts to promote engagement of patients and the public in health research and technology assessment are also ongoing in other regions including, but not limited to, Latin America and Asia.^{22,23}

There is broad agreement that patient engagement should be meaningful, impactful, and measurable; however, terms related to patient engagement and patient-centeredness are used inconsistently across stakeholders and contexts.^{7,24,25} These terms are rarely defined and may be used synonymously with related, but distinct, concepts. For example, patient engagement is frequently used interchangeably with patient activation, patient involvement, and patient-centered care.¹⁹ A horizon scan of terms and definitions related to patient engagement identified 24 terms, each with multiple definitions across healthcare sectors (eg, government agencies, payers, and patient advocacy groups).²⁶ Additionally, these terms and definitions may be context specific, with variable meanings. As such, it is possible that a high-quality definition of patient engagement in the context of healthcare delivery context may not always be appropriate for use in the context of research.

Health economics and outcomes research (HEOR) stakeholders, including researchers, clinicians, patients, payers, regulators, and industry, are seeking to meaningfully partner with patients to incorporate patient input into their research.^{27–29}

Clarity on what patient centeredness and patient engagement mean in the context of health economics and outcomes research is increasingly relevant for members of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and similar research organizations.²⁹ To ensure clear and consistent communication, an ISPOR standard definition for these terms is desirable for use in ISPOR communications, task forces, and other Society initiatives. Such a definition would also support efforts to identify and measure quality patient engagement activities.

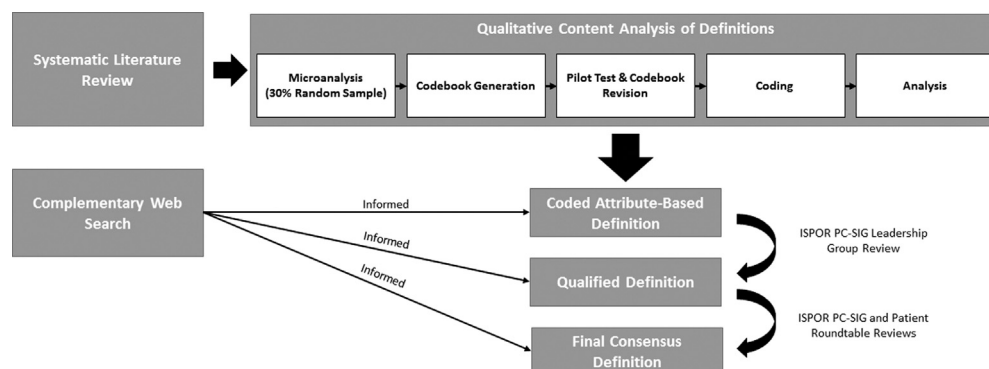
To this end, the Patient Engagement in Research Working Group of the ISPOR Patient-Centered Special Interest Group (PCSIG) set out to conduct a comprehensive review of existing definitions of patient engagement, patient-centeredness, and related concepts, with the goal of generating a robust, evidence-based, scalable definition of patient engagement fit for use in the context of health research.

Methods

A multistep data extraction, review, and analysis process was undertaken to generate a final definition (Fig. 1). It was determined from the outset that, to ensure an adequate identification and coding process, a multistakeholder approach representing the perspectives of researchers (both academic and industry) and patients was required. To this end, a study team representing all of these groups was maintained across design, methods selection, analysis, and interpretation. It included both the systematic review and qualitative analysis research teams, as well as the stakeholders who reviewed the final definition.

Before initiating the systematic review, a targeted web search was first conducted to identify relevant terms, definitions, and frameworks in grey literature (eg, web-based documents from patient advocacy groups and umbrella patient advocacy organizations, as well as health authorities and regulators). Grey literature was deemed important for this scoping review given the possible underrepresentation of these stakeholders in the published literature. This literature was identified through either a recommendation from the authors or a general text search using Google and Google Scholar to identify relevant definitions from other web sources. The search was limited to the English language. As a result, definitions for patient engagement and patient-centeredness represented by public and private organizations globally were recorded and new patient-related terms were identified for inclusion in the systematic review search criteria. These definitions were also used to externally validate findings from the systematic review and to support further definition development.

Figure 1. Diagram depicting the multistep process followed to achieve final proposed definition of “patient engagement in research.”



Systematic Review

We conducted a PubMed and EMBASE database search for titles and abstracts that included the terms “patient engagement,” “patient-centeredness,” or related patient terms in published literature from January 1, 2006, through December 31, 2016 (see [Appendix 1](#) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2020.01.019>). The choice of 2006 as the start of the review period was based on an examination of the prevalence of the terms of interest in the peer-reviewed literature, which identified an increase in the mid-2000s. In addition, because terms have evolved over time, the intent was to focus on contemporary usage and meanings. To reflect the evolving nature of this topic, an update of the review specific to the “patient engagement” and “research” search criteria was conducted for the period between January 1, 2017, and December 31, 2018. Results of this extended search were integrated into the complete analysis. Published literature was limited to the English language to accurately interpret and code the definitions. To manage the anticipated high volume of articles, the full review team consisted of 16 PCSIG members who were assigned in pairs to independently screen each abstract for relevance. Any disagreements were resolved by consensus. A third researcher resolved any remaining discrepancies.

Criteria for selecting abstracts for full-text review were established a priori and defined as follows.

Inclusion Criteria:

1. At least 1 definition of a term was in the abstract.
2. The purpose/objective of the article was to define the term or introduce, examine, or analyze a conceptual model or framework.
3. The article was a systematic review of the term definition or concept.
4. It was an opinion article about the term’s use or importance in healthcare or health research.
5. It was unclear whether to include it without a full-text review.
6. The publication year was 2006 or later.

Exclusion Criteria:

1. No patient terms were defined or framework was referenced.
2. It was not healthcare or health-research related.
3. The term was used to describe a treatment approach or intervention in a specified population (eg, colorectal surgery) without defining the term.
4. The term was used in the context of improved communications or infrastructure of an organization through information technology (eg, patient portals, electronic health records [EHRs], devices, equipment, web-based tools) without defining the term.

Abstracts designated for full-text article review were then assessed independently by 2 data abstractors. During full-text review, the same inclusion and exclusion criteria were applied to identify the final analytic set. Identified terms and their definitions were categorized by whether the definition was adapted or adopted from another referenced source or the article authors provided an original definition. Abstractors also recorded the context in which the definitions were used, (ie, healthcare delivery, research, both, or other). If the article provided a framework for the definition, this was also recorded. A single article could contribute more than 1 definition.

To account for definitions that were adopted multiple times from the same referenced source, either the source reference of the original definition or the first published record of the definition in the study period was retained in the final analysis. This deduplication process resulted in additional exclusions.

Qualitative Content Analysis

Definitions for each patient-related term abstracted from a full-text article review underwent qualitative content analysis (QCA).³⁰ The full review team consisted of 6 individuals. Reviewers, assigned in pairs, assessed each definition, with a third reviewer available to resolve any discrepancies. Analysis was conducted as an iterative process, with the coding framework (ie, codebook) derived inductively from the definition content.³¹ Microanalysis, a detailed form of open coding used to generate ideas, was performed on a random 30% sample of definitions to extract and consolidate concepts and develop a preliminary codebook.³² This initial codebook was piloted on a subset of definitions and was extended and modified based on reviewer feedback to generate a final coding dictionary ([Table 1](#); see also [Appendix 2](#) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2020.01.019>). Complete coding on the full definition set was then conducted.

The stakeholders involved in engagement (the “who”) were differentiated based on their identified role, either as the party responsible for conducting engagement (the conductor) or the party targeted to be engaged (the target). Stage of activity (the “when”) was conceptualized as a timeline.³³ Stages were identified (from earliest to latest) as: “Strategy & Priority Setting,” “Design & Planning,” “Conduct & Operation,” “Dissemination & Communication,” and “In Practice/In Use.” Additionally, the stage could be identified as “All” should a definition refer to all stages across the timeline.

Upon finishing coding and reaching saturation for each patient term (no new concepts identified within the term), the resulting codes were discussed with the full research team to examine the similarities and dissimilarities of coded content within and between patient terms. As a result, similar or overlapping codes were grouped into meaningful attributes, such as “communication: accessible,” “decision making: shared” and “empowerment” (for further detail, see [Appendices 2](#) and [3](#) in Supplemental Materials).³⁰ Patient terms with near-identical attributes were consolidated into one patient term.

Descriptive analyses, including frequency and relative ranks of coded concepts, were conducted overall by patient term and by primary coding categories (eg, context of use, target audience of engagement, stage of activity). Definition coding was conducted using Microsoft Excel and analysis was performed using SAS® version 9.4.

Definition Review and Consensus

After completion of QCA, a preliminary definition of “patient engagement in research” was generated based on the most prevalent coded characteristics of definitions of patient engagement and definitions in the research setting. This preliminary definition was then reviewed by the ISPOR PCSIG Leadership Group to ensure conceptual clarity, minimize repetition, and supplement with relevant context from other defined terms. This revised definition was proposed to the full PCSIG (n = 447 internationally) and to the participants of the past 10 ISPOR Patient Representatives Roundtables (n = 157), including North America, Europe, and Latin America. A final consensus definition was derived based on stakeholder feedback.

Results

Systematic Review

A total of 1882 articles were identified in the search (PUBMED: 1405; EMBASE: 334; Other: 8). After deduplication, 1821 unique abstracts were screened for relevance, and ultimately 317 full-text

Table 1. Qualitative analysis codebook structure.

Category	Content	Required*	No. of Allowed Terms per Definition	No. of Terms in Code List [†]
Defined Term (What)	The search term that produced the definition	Yes	1	12
Characteristics (How)	The defined process, activities or expectations	Yes	8	51
Rationale (Why)	The defined goals of the activity	No	3	51
Setting (Where)	The defined setting or context of use	No	2	7
Conductor of Engagement (Who)	The defined conductor (“engager”) the activity	No	3	7
Target of Engagement (Who)	The defined target (“engagee”) the activity	No	3	6
Stage of Activity (When)	The defined point in the process at which the activity occurs	No	3	6

*Required indicates at least one term must be coded in the field for the definition to be included in the analysis and considered “informative.”

[†]Reflects number of high-level terms in each code list. Refer to [Appendix 2](#) in Supplemental Materials for additional information.

articles were reviewed for definitions. Out of a final set of 169 articles, 244 distinct definitions across all search terms were identified for analysis (Fig. 2). The most frequently referenced “adopted” definition was from the Institute of Medicine, followed by the one by Stewart et al.^{34,35} The majority of articles were published between 2012 and 2015, with 2012 being the year with the highest number of publications offering definitions (Table 2). The search term contributing the most articles was “patient-centered” (26.8%), followed by “patient engagement” (16.7%).

Qualitative Content Analysis

Qualitative content analysis was conducted on 244 definitions. Of those, 17.2% were extracted from articles identified by the search term “patient engagement,” 43.4% identified by the search term “patient-centered,” and 39.3% split among other terms. The most frequent setting of the activity, overall, was healthcare at 70.5%, with the research setting identified in only 11.9% of definitions.

The 3 most common characteristics, overall, were “patient as participant,” “patient involvement,” and “incorporate patient: preferences” and “relationship: patient-provider” (tied). Although the top 10 characteristics were similar across defined terms, relative rankings differed (Table 3). The most prevalent characteristics among definitions of patient engagement were “process: active,” “patient involvement,” and “patient as participant.” The top patient-centered definition characteristics were “incorporate patient: preferences,” “incorporate patient: perspective,” and “relationship: patient-provider.” There were also differences between the settings (Table 4). The top 3 characteristics of definitions in the research setting were “patient involvement,” “patient as partner,” and “process: active.” In healthcare, they were “relationship: patient-provider,” “patient as participant,” and “incorporate patient: preferences.” Four characteristics appeared in the overall top 10 and were never coded among definitions in the research setting: “individualized approach: care,” “patient in control,” “patient as person,” and “respect.”

Overall, “patients” were the most common target of engagement (83.7%). Among these definitions, the target was further defined in a majority of cases. The most common characterization of patients was “patient community, in general” (38.8%), “individual patient” (29.6%), and “patient advocacy/advocates” (1.5%). Family or caregivers were identified as a target of the

activity in only 8.2% of definitions (n = 19 and n = 1, respectively). When possible, conductors of engagement were identified within definitions. The most common were healthcare practitioners (35.7%) and the healthcare system (22.1%). Patients, traditionally a “target” of engagement, were identified as the party responsible for conducting engagement activities in 17.2% of definitions.

The most common stage of activity identified among definitions was “In Practice/In Use” (the latest stage). Only 5.7% of definitions identified activities at the “Strategy & Priority Setting” stage; however, those that fell into the patient engagement term definition and research setting had the highest proportion compared with other terms or settings (9.5% and 10.3%, respectively). Among definitions in the research setting, 34.5% identified activity across “All Stages,” compared with only 2.9% of definitions in the Healthcare setting.

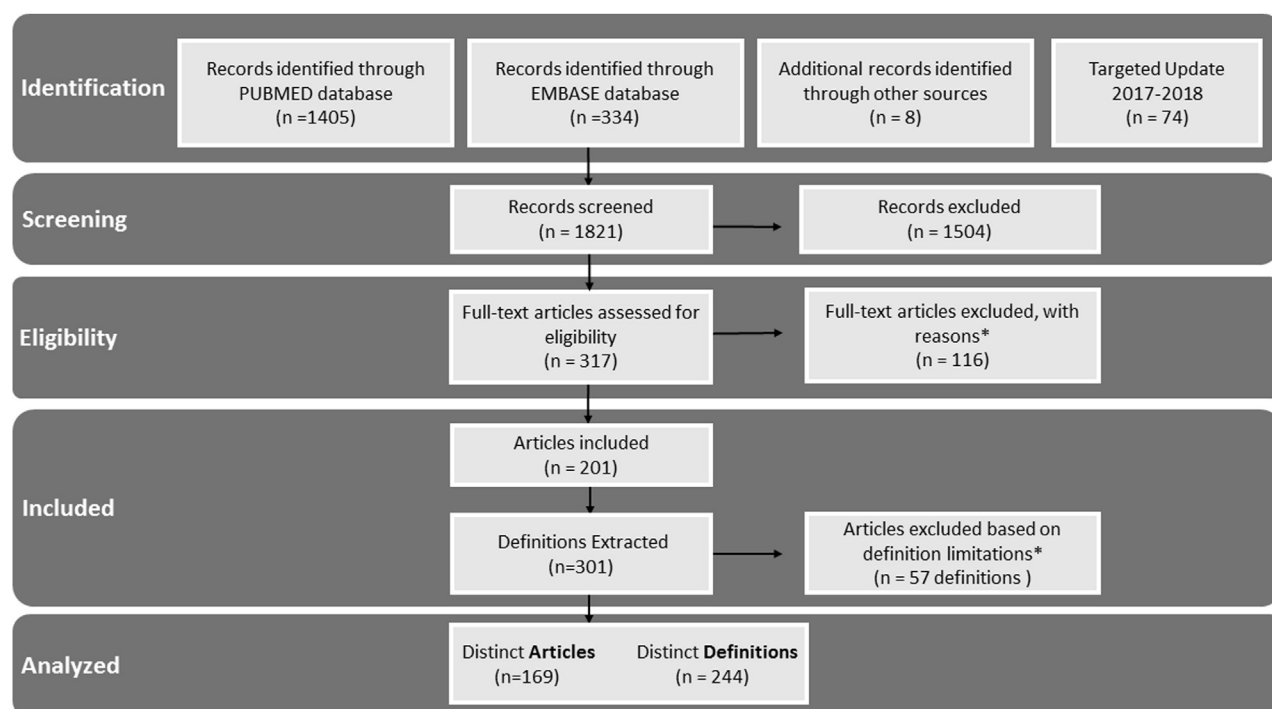
Generally, the proportion of definitions in which a characteristic could not be identified (ie, “Undetermined”) was less than 20%: “Setting of Activity” (13.1%), “Target of Engagement” (13.9%), and “Stage of Activity” (19.3%). “Conductor of Activity,” on the other hand, could not be determined in 36.1% of definitions.

We also examined the overlap of concepts between the term “patient engagement” and the research setting. The term “active process” was ranked first among concepts related to the defined term “patient engagement” and third among defined terms in the research setting. Similarly, “meaningful to patient” was ranked fifth and seventh, respectively. Although the overall occurrence of engagement across “All Stages” was low (6.6%), it was the most prevalent stage of engagement among research setting definitions (34.5%) and the highest among the definitions of “patient engagement” (11.9%), compared with other terms.

Proposed Definition of Patient Engagement in Research

A working definition was constructed based on cross-tabulated frequencies and shared ranking of coded terms in the patient engagement and research categories. The authors made modifications to this QCA-constructed definition, informed by results from the grey literature scan and by review of prevalent themes unique to the defined term “patient engagement” or the setting of research, excluding overlapping themes.^{36–39} This revised definition was then provided to the full PCSIG membership, as well as to members of the 4 regional ISPOR Patient Representatives

Figure 2. Identification and selection of articles into systematic review and analysis attrition diagram. *Refer to [Appendix 1 in Supplemental Material](#) for details on exclusion reasons and counts.



Roundtables (see [Appendix 4](#) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2020.01.019>). Comments were received from 24 reviewers, who self-identified as representing the following perspectives: patient representatives (42%), academicians/researchers (29%), industry (12.5%), health technology

assessment (HTA) bodies (8%), regulatory/government (4%), and other (4%). The following regions were represented: North America (32%), Latin America (32%), Europe (24%), Asia (8%). The PCSIG Leadership Group then reviewed all comments and feedback, from which a final consensus definition was derived.

Table 2. Characteristics of articles identified by systematic review.

Search Terms	No. of Articles*	Average year of publication	References
<i>Overall</i>	169	2012	-
Patient-Centered	49	2012	19,51-98
Patient Engagement	30	2014	2,13,19,99-125
Patient Involvement	25	2011	91,126-149
Patient Participation	24	2011	55,66,69,140,150-169
Patient Empowerment	21	2011	52,158,170-188
Patient-Centeredness	18	2012	13,70,79,94,106,179,189-200
Person-Centered	10	2012	88,201-209
Patient Focused	4	2012	13,203,210,211
Patient-Centric	3	2009	212-214
Consumer Involvement	2	2008	63,215
Patient Input	1	2011	216
Patient Oriented	1	2013	217
Consumer Engagement	1	2010	218

Note. For purposes of analysis and presentation of results, the following terms were combined: Patient Focused & Patient-Focused Drug Development & Patient-Focused Outcomes Research; Patient-Centered & Patient-Centered Outcomes Research

*A single article could contribute multiple definitions. The overall total reflects the total number of distinct articles. The term-specific number of articles reflects the number of distinct articles contributing a definition for that term.

Table 3. Identified characteristics of definitions, overall and by defined term.

Definitions, Overall	Overall			Patient Engagement			Patient-Centered*			Other		
	Rank	n	%	Rank	n	%	Rank	n	%	Rank	n	%
		244	-		42	17.2		106	43.4		96	39.3
Top Characteristics of Activity												
patient as participant	1	43	17.6	3	9	21.4	8	13	12.3	1	21	21.9
patient involvement	2	36	14.8	2	10	23.8	8	13	12.3	4	13	13.5
incorporate patient: preferences	3	35	14.3	6	4	9.5	1	26	24.5	11	5	5.2
relationship: patient-provider	3	35	14.3	6	4	9.5	3	21	19.8	6	10	10.4
Decision making: shared	4	33	13.5	5	6	14.3	8	13	12.3	3	14	14.6
patient as partner	5	32	13.1	4	8	19.0	7	14	13.2	6	10	10.4
incorporate patient: perspective	6	27	11.1	9	1	2.4	2	23	21.7	13	3	3.1
process: active	6	27	11.1	1	12	28.6	19	2	1.9	4	13	13.5
individualized approach: care	7	22	9.0	9	1	2.4	4	18	17.0	13	3	3.1
information sharing	8	20	8.2	7	3	7.1	17	4	3.8	4	13	13.5
patient in control	8	20	8.2	8	2	4.8	19	2	1.9	2	16	16.7
understanding	8	20	8.2	9	1	2.4	5	16	15.1	13	3	3.1
patient as person	9	17	7.0	9	1	2.4	6	15	14.2	15	1	1.0
Decision making: informed/competent	10	16	6.6	7	3	7.1	15	6	5.7	9	7	7.3
empowerment	10	16	6.6	7	3	7.1	20	1	0.9	5	12	12.5
process: adaptive/responsive	10	16	6.6	n/a	0	0.0	10	11	10.4	11	5	5.2
respect	10	16	6.6	9	1	2.4	9	12	11.3	13	3	3.1
Stage of Activity[†]												
5) In Practice/In Use	1	156	63.9	1	22	52.4	1	84	79.2	1	50	52.1
Undetermined	2	47	19.3	3	9	21.4	2	14	13.2	2	24	25.0
2) Design & Planning	3	30	12.3	2	10	23.8	3	11	10.4	3	9	9.4
All	4	16	6.6	4	5	11.9	5	3	2.8	4	8	8.3
1) Strategy & Priority Setting	5	14	5.7	5	4	9.5	4	4	3.8	5	6	6.3
3) Conduct & Operation	6	13	5.3	5	4	9.5	7	1	0.9	4	8	8.3
4) Dissemination & Communication	7	6	2.5	6	2	4.8	6	2	1.9	6	2	2.1
Setting of Activity												
Healthcare	1	172	70.5	1	27	64.3	1	88	83.0	1	57	59.4
Undetermined	2	32	13.1	3	2	4.8	2	12	11.3	2	18	18.8
Research	3	29	11.9	2	12	28.6	3	5	4.7	3	12	12.5
Other	4	11	4.5	4	1	2.4	4	1	0.9	4	9	9.4
Target of Engagement												
Patient	1	206	84.4	1	38	90.5	1	99	93.4	1	69	71.9
Undetermined	2	34	13.9	2	6	14.3	3	8	7.5	2	20	20.8
Family	3	19	7.8	3	5	11.9	2	10	9.4	4	4	4.2
Public	4	15	6.1	5	2	4.8	6	2	1.9	3	11	11.5
Provider	5	9	3.7	6	1	2.4	4	4	3.8	4	4	4.2
Stakeholder (otherwise undefined)	6	8	3.3	4	3	7.1	5	3	2.8	5	2	2.1
Caregiver	7	1	0.4	7	0	0.0	7	1	0.9	6	0	0.0
Conductor of Engagement												
Undetermined	1	88	36.1	1	13	31.0	2	33	31.1	1	42	43.8
Healthcare Practitioner	2	87	35.7	5	8	19.0	1	56	52.8	3	23	24.0
Healthcare System	3	54	22.1	4	9	21.4	3	28	26.4	4	17	17.7
Patient	4	42	17.2	3	10	23.8	4	7	6.6	2	25	26.0
Researcher	5	21	8.6	2	11	26.2	5	4	3.8	5	6	6.3
Provider Organization	6	5	2.0	6	2	4.8	6	3	2.8	8	0	0.0
Government	7	4	1.6	7	0	0.0	7	0	0.0	6	4	4.2
Industry / Commercial	8	3	1.2	7	0	0.0	7	0	0.0	7	3	3.1

Note. Percentage represents percent of definitions in which the term appears.

*Combination of patient: centered, centeredness, centric, and person-centered

[†]Note that a single definition could have multiples stages, targets, and conductors, so percentages may add up to more than 100%.

As a result of this process, we propose the following definition of “patient engagement in research”:

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.

It is important to clarify key concepts within this definition. First, the term “patients” is used inclusively to represent

individual patients, their families, and their caregivers, in addition to patient representatives and advocacy organizations. This is in line with other work in this space.^{40,41} The term “researchers” is also used broadly to refer to multiple contributors within the process, such as research producers (those directly conducting the research activity) and decision-making consumers (such as payers and regulators). Research funders, through their role in priority setting and protocol review, should also be held accountable for ensuring engagement is

Table 4. Identified characteristics of definitions, overall and by setting of activity.

Definitions, Overall	Overall			Research			Healthcare			Other*		
	Rank	n	%	Rank	n	%	Rank	n	%	Rank	n	%
		244	-		29	11.9		172	70.5		43	17.6
Top Characteristics of Activity												
patient as participant	1	43	17.6	4	5	17.2	2	53	30.8	1	21	48.8
patient involvement	2	36	14.8	2	8	27.6	4	37	21.5	1	21	48.8
incorporate patient: preferences	3	35	14.3	7	2	6.9	3	52	30.2	6	10	23.3
relationship: patient-provider	3	35	14.3	7	2	6.9	1	54	31.4	5	11	25.6
decision making: shared	4	33	13.5	7	2	6.9	6	32	18.6	2	19	44.2
patient as partner	5	32	13.1	1	10	34.5	7	30	17.4	3	15	34.9
incorporate patient: perspective	6	27	11.1	5	4	13.8	5	34	19.8	7	9	20.9
process: active	6	27	11.1	3	6	20.7	8	29	16.9	5	11	25.6
individualized approach: care	7	22	9.0	9	0	0.0	8	29	16.9	6	10	23.3
information sharing	8	20	8.2	6	3	10.3	12	19	11.0	3	15	34.9
patient in control	8	20	8.2	9	0	0.0	12	19	11.0	3	15	34.9
understanding	8	20	8.2	8	1	3.4	11	20	11.6	4	13	30.2
patient as person	9	17	7.0	9	0	0.0	10	21	12.2	7	9	20.9
decision making: informed/competent	10	16	6.6	8	1	3.4	13	18	10.5	9	7	16.3
empowerment	10	16	6.6	7	2	6.9	10	21	12.2	10	6	14.0
process: adaptive/responsive	10	16	6.6	8	1	3.4	12	19	11.0	8	8	18.6
respect	10	16	6.6	9	0	0.0	9	23	13.4	11	5	11.6
Most Prevalent Stage of Activity												
5) In Practice/In Use	1	156	63.9	3	4	13.8	1	141	82.0	2	11	25.6
Undetermined	2	47	19.3	3	4	13.8	2	18	10.5	1	25	58.1
2) Design & Planning	3	30	12.3	2	9	31.0	2	18	10.5	3	3	7.0
All	4	16	6.6	1	10	34.5	5	5	2.9	5	1	2.3
1) Strategy & Priority Setting	5	14	5.7	4	3	10.3	3	8	4.7	3	3	7.0
3) Conduct & Operation	6	13	5.3	3	4	13.8	4	7	4.1	4	2	4.7
4) Dissemination & Communication	7	6	2.5	3	4	13.8	6	2	1.2	6	0	0.0
Target of Engagement												
Patient	1	206	84.4	1	26	89.7	1	156	90.7	1	24	55.8
Undetermined	2	34	13.9	4	3	10.3	3	16	9.3	2	15	34.9
Family	3	19	7.8	5	1	3.4	2	17	9.9	4	1	2.3
Public	4	15	6.1	2	5	17.2	5	4	2.3	3	6	14.0
Provider	5	9	3.7	5	1	3.4	4	8	4.7	5	0	0.0
Stakeholder (otherwise undefined)	6	8	3.3	3	4	13.8	6	3	1.7	4	1	2.3
Caregiver	7	1	0.4	5	1	3.4	7	0	0.0	5	0	0.0
Conductor of Engagement												
Undetermined	1	88	36.1	3	5	17.2		51	29.7		32	74.4
Healthcare Practitioner	2	87	35.7	4	2	6.9		84	48.8		1	2.3
Healthcare System	3	54	22.1	4	2	6.9		46	26.7		6	14.0
Patient	4	42	17.2	2	6	20.7		28	16.3		8	18.6
Researcher	5	21	8.6	1	20	69.0		0	0.0		1	2.3
Provider Organization	6	5	2.0	6	0	0.0		5	2.9		0	0.0
Government	7	4	1.6	6	0	0.0		2	1.2		2	4.7
Industry / Commercial	8	3	1.2	5	1	3.4		1	0.6		1	2.3

*Combination of patient *centered, *centeredness, *centric, and person-centered

appropriately defined. Different patient and researcher representatives may be involved at different stages in the research process. For example, funding bodies may be more involved during priority setting stages whereas payers may be more involved in implementation and dissemination.

By incorporating “all stages of the research process,” we intend to cover the full spectrum of research activities, including planning, conduct, and dissemination. The phrase “all stages” is used to indicate that patient engagement may be possible, and should be considered, at any point in a study. Nevertheless, it is not meant to function as a mandate that engagement must happen at all stages of a single study, which may be neither feasible nor appropriate. By characterizing

engagement as “active, meaningful, and collaborative,” the definition reflects the importance of substantive, versus superficial, interactions.^{42,43}

Finally, it is essential to describe what is meant by “patients’ contributions.” This concept is not intended to reflect patient-level clinical information collected as part of a research study, (ie, the patient as a passive “data point” contributor). Rather, patient contributions include capturing and utilizing patient perspectives, preferences, experiences, opinions, and inputs into the research itself. These may be captured formally (eg, preference elicitation methods, focus groups, advisory board membership), or informally (eg, through routine interactions that evolve as part of research partnerships).

Discussion

We propose a standardized definition of “patient engagement in research” derived from the results of our analysis, further informed by the results of an environmental scan and by the review of multiple stakeholder groups. It is intended to be aspirational and represent what full patient engagement in research should look like. The goal of engagement should be a partnership, where patient contributions are given equal weight to those of other contributors to the research team. We recognize that external constraints may present challenges at first, and that different forms of engagement may be needed to support different types of research activities. Results of our review emphasize the importance of inclusion, respect, and equality in the interactions between patients and researchers.

Previous studies have highlighted the (possibly inappropriate) interchangeable use of different terms related to patient engagement.^{19,44} This was substantiated by our analysis, where a clear distinction emerged between the terms “patient-centered” and “patient engagement.” “Patient-centered” was more focused on the healthcare setting in a patient-provider context. Compared with other defined terms, “patient engagement” was most strongly associated with an active, involved process. We also found evidence of comprehensive engagement across stages in the research setting compared with a healthcare setting.

Our study benefits from a number of strengths. A multi-stakeholder approach was taken at all stages, from study design through execution and dissemination, with a focus on transparency and collaboration. This is the first study to conduct a systematic review or qualitative analysis of the literature in this space. Rubrics and frameworks can be critical for measurement. Nevertheless, the lack of a clear, concise definition has presented a barrier to uptake as stakeholders, particularly on the researcher side, struggle to implement patient engagement in research in their organizations. We conducted an analysis of concepts unique to research to allow for a targeted definition, rather than relying on concepts more appropriate to the provision of patient-level healthcare. The proposed definition is concise and can be used without reference to external frameworks or conceptual models. Our definition aligns closely with ongoing complementary initiatives by researchers, health authorities, and patient organizations. This includes distinguishing between “patient-provided information” (eg, patient preferences, feedback on design) and “patient medical information” (eg, clinical endpoints or measures), the incorporation of “specific knowledge and expertise” brought by patients to scientific discussion, and the importance of engagement throughout the entire research process.^{15,25,29,41,45}

Results of our review are subject to limitations. This review was limited to English language literature. Although the volume of articles suggests this represents a large share of the work in this area, there is a possibility that unique concepts not present in the English literature were missed. Moreover, the volume of articles and definitions to be reviewed, and challenges related to the availability of study team members who volunteered their time, meant it took a considerably longer time to execute the study than originally anticipated. As a result, the literature review (which included publications available as of December 31, 2018) does not reflect more recent publications. Nevertheless, the previously highlighted consistency of our results with contemporary work in this space suggests consistency in themes. Given the large scope of the published literature review, full qualitative content analysis was not conducted on sources from the nonpublished literature (eg, patient advocacy websites and white papers). The final

proposed definition, however, was reviewed against the grey literature identified by the complementary web search. Finally, QCA coding terms were defined based on a detailed microanalysis of the review-identified definitions. It is possible that coding terms were identified that reflected the reviewer’s understanding, but not the author’s original intent, for a given definition. The discrete nature of the coding may also not reflect the full nuances of the field.

As a next step, results of this work could be used to inform companion definitions to the one proposed for “patient engagement in research.” In particular, a definition of “patient-centered research” would help provide context for use of these separate terms and explore alignment between concepts.

Conclusions

The ability for patient engagement to improve research is only as good as how it is defined and operationalized and will be limited if stakeholder understanding of engagement is convoluted or misunderstood. Based on our analysis from a systematic literature review, we offer a standardized definition of “patient engagement in research” that can be adopted by various stakeholders across the research continuum.

Several next steps should be taken to continue moving understanding and implementation of patient engagement in research forward. Most pressingly, there is a need to determine how to operationalize, implement, and measure the success of patient-engagement initiatives and to learn from any challenges. Such an activity must account for what “good” engagement looks like from both the researcher and patient perspectives. This work has already begun among some stakeholder groups, including professional and research organizations, who play an important role in shaping the dialogue and scientific standards in their fields.^{45–48} For example, the Patient-Centered Outcomes Research Institute Engagement Rubric provides examples of how to operationalize the role of “patient as partner.”³⁶ Revisiting activities based on a standardized definition and understanding of engagement would assist in moving the process forward. The time and resources needed for patients to engage in research must be considered and respected, with appropriate support (financial and otherwise) and training provided. Finally, field-specific gaps in the uptake of engagement should be identified, and work should be undertaken to resolve them.⁴⁹ For instance, the lack of relevance of research to patients has been noted as a barrier to patient use of comparative effectiveness research.⁵⁰ This includes failure to communicate in lay language.

These future activities must not occur in siloes. Many stakeholders in this space are contributing to the evolving science and philosophy of patient engagement. This breadth of contributions brings many benefits but also the risk of fragmentation. Collaboration between contributors across stakeholder perspectives, regions, and organizations can lead to a more robust and consistent path forward. Finally, it should be noted that patient engagement in research is not a static concept. Although our proposed definition is aspirational, there remains room for further development as the research environment continues to evolve. Patients and patient organizations have demonstrated a strong desire and growing capability to become drivers and leaders in research. The outlook for patient engagement in research may look different in the near future. It is incumbent upon researchers to consider the impact of this change and not only ask how patients can inform their research agenda, but also how they can support the research agenda of patients directly.

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