



Rethinking Patient Engagement in Cancer Research

Anne L. R. Schuster¹ · Heather Hampel^{2,3} · Electra D. Paskett^{4,5} · John F. P. Bridges¹

Accepted: 20 September 2022 / Published online: 27 October 2022
© The Author(s) 2022

1 Introduction

Patient engagement is an increasingly prominent topic in cancer research. In the US, this is exemplified by the Cancer Moonshot, a national initiative funded in 2016 to accelerate scientific discoveries in cancer and which funds a federated network for ‘direct’ patient engagement [1]. Several research programs are part of the Cancer Moonshot’s federated network for direct patient engagement; they intend to promote access to cancer genomics research, especially among patients from underserved and historically underrepresented populations [2]. Despite this attention towards direct patient engagement, there is no explicit explanation of this non-standard term [3].

However, the meaning of the more commonly used term ‘patient engagement in research’ also lacks clarity. The concept falls within a broader literature on the systematic integration of the patient voice in areas such as precision cancer medicine and regulatory decision making [4–8]. Globally, patient engagement in research is supported through national-level infrastructure [9–11] and prominent initiatives such as the Patient Focused Medicines Development (PFMD) initiative in the EU. Since 2016, the PFMD has worked to build a framework for patient engagement throughout the medicine development lifecycle [12, 13], yet does not define the term. The meanings of the term patient engagement in research are also varied in the empirical

literature but often emphasize patients in active roles as integral contributors to the design, conduct, and dissemination of research [14, 15].

Inconsistent definitions present challenges for operationalizing and measuring patient engagement [10]. Given the increased attention to patient engagement in cancer research, there is an opportunity to revisit what the term means. The purpose of this paper was to draw on the origins of the term ‘engagement’ [16] and its use in different academic disciplines to synthesize conceptualizations of the term. The intent is to broaden the conversation about the meaning of engagement and consider the implications for conceptually defining patient engagement in cancer research. Doing so will allow us to realize how we may fully enact and study patient engagement in cancer research.

2 Meanings of the Term ‘Engagement’

Figure 1 depicts concepts used to describe the term ‘engagement’ over time. Engagement as a term dates back to the 17th century, with its use to describe concepts such as military conflicts, moral or legal obligations, or formal promises such as political compacts and treaties [16]. Over time it has been used to refer to a sense of attachment, being betrothed to be married, or being employed by being in a salaried ‘appointment’ or job [16]. It is still used in many of these ways but new meanings have developed, such as a person’s ‘attention’ or their ‘involvement’. Additionally, engagement has taken on meanings about developing a sense of connection over time [17, 18].

The term ‘engagement’ has also been used in a range of academic disciplines, such as marketing [19–21], education [22–24], information systems [25, 26], and organizational behavior [27]. The field of marketing has explored ‘consumer engagement’ and the field of education studies ‘student engagement’. The information systems field explores ‘user engagement’ in human-technology interactions, and the organizational behavior field considers ways to encourage ‘employee engagement’. Evidence indicates that

✉ Anne L. R. Schuster
anne.schuster@osumc.edu

¹ Department of Biomedical Informatics, College of Medicine, The Ohio State University, Lincoln Tower, 1800 Cannon Drive, Columbus, OH, USA

² Division of Clinical Cancer Genomics, City of Hope National Medical Center, Duarte, CA, USA

³ Division of Human Genetics, The Ohio State University College of Medicine, Columbus, OH, USA

⁴ Division of Cancer Prevention and Control, Department of Internal Medicine, College of Medicine, The Ohio State University, Columbus, OH, USA

⁵ Division of Epidemiology, College of Public Health, The Ohio State University, Columbus, OH, USA

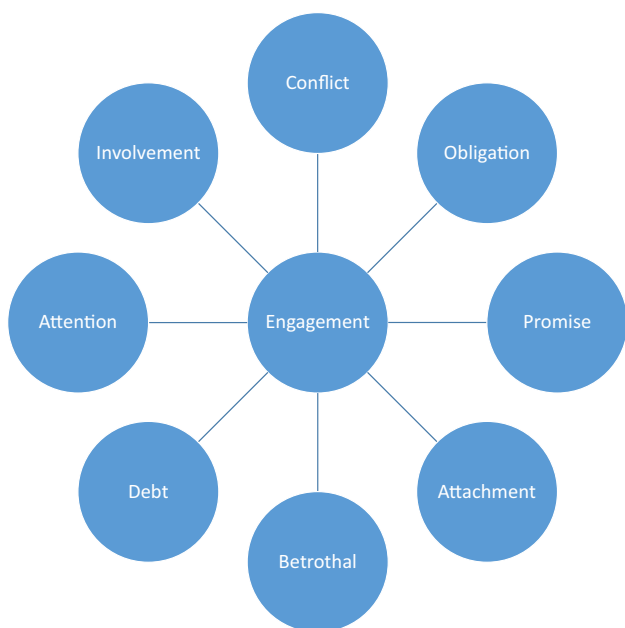


Fig. 1 Multiple facets of the term engagement

disciplines vary in the extent to which they have systematically conceptualized engagement [19, 28].

3 Two Conceptualizations of Engagement

Engagement is generally conceptualized in two, interdependent ways: as a state, and as a process [28]. Both come about through interactions, which are the interplay between materials, other people, or the social setting where an experience occurs. As a state, engagement refers to the cognitive and emotional conditions experienced by an individual that can be expressed through observable behaviors [27, 29–32]. The process of engagement refers to different stages of becoming engaged, staying engaged, disengaging, and re-engaging, which occur over the short- and long-term [25, 33, 34]. These two conceptualizations of engagement are interdependent and are described in further detail below, with representative definitions provided from diverse academic disciplines: marketing, education, information systems, and

organizational behavior. Table 1 provides an overview of key aspects of these two conceptualizations. Some literature on employee engagement also refers to engagement as a trait, but this was not reflected in definitions from other disciplines.

3.1 The State of Engagement

The state of engagement is described as a multifaceted construct comprised of cognitive, emotional, and/or behavioral dimensions [28, 30]. This conceptualization of engagement is illustrated by William Kahn in his seminal work on employee’s personal engagement with their work [32]. Kahn described employee’s engagement at work as the cognitive, emotional, and physical expression of their authentic self [32]. When people personally engage in their work, he reported that they are energetic, cognitively vigilant, and empathically connected with others [32]. In consumer engagement, the dimensions of engagement as a state have been described as how much consumers think about a brand (i.e., cognitive engagement); what consumers feel about a brand (emotional engagement); and how much energy, time, and effort consumers put towards using a brand or referring others to the brand (behavioral engagement) [35]. Similarly, student engagement is defined as “the energy and effort that students employ within their learning community” [29] and measured via characteristics such as a student’s sense of challenge, delight, and immersion with any given activity.

Every interaction is an opportunity to foster a state of engagement that in turn can create a sense of trust, satisfaction, and emotional attachment [36]. A pivotal article on consumer engagement by Brodie and colleagues indicated that the state of engagement “occurs by virtue of interactive, co-creative customer experiences with a brand” [31]. These interactive experiences have been described as including consumer-to-consumer interactions in brand-related chat rooms or on blogs, as well as through interactions via online feedback forms [37]. In the context of student engagement, scholars note that engagement “is shaped by a range of structural and internal influences, including the complex interplay of relationships, learning activities and the learning environment” [29].

Table 1 Two conceptualizations of engagement

State of engagement	Process of engagement
Comprised of internal cognitive and emotional experiences (e.g., enjoyment or mental stimulation) and behaviors (e.g., participation)	Progresses through stages of becoming engaged, staying engaged, disengaging, and re-engaging
Response to every interaction that can lead to relational outcomes such as trust and attachment	Experiences accumulate and influence long-term re-engagement via cyclical ‘feedback loops’
Transient, context-dependent, and varied in its intensity at any given point in time	Actively co-created where stages of engagement are influenced by factors intrinsic and extrinsic to patients

The state of engagement is transient, context-dependent, and varied in its intensity at any given point in time. For example, in the literature on employee engagement, levels of engagement vary across time and in response to contextual factors, including employees' feelings about their psychological safety, the availability of needed resources, and the meaningfulness of the work [32]. Similarly, Nolan et al. suggest that customers engage in online communities when the perceived level of value outweighs the perceived level of risk [38].

3.2 The Process of Engagement

Engagement as a process is iterative, dynamic, and relational [25, 28]. In the field of information systems, O'Brien and Toms identified four distinct stages of engagement: point of engagement, period of sustained engagement, disengagement, and re-engagement [25]. These stages can refer to both isolated and ongoing interactions over time. This is also apparent in the consumer engagement literature. For instance, Bowden models 'customer engagement' as an iterative 'psychological process'. Bowden's model traces how cognitive and emotional dimensions of engagement support the stages of the customer lifecycle as new customers make the transition to becoming sustained customers [34].

The process of engagement is actively co-created. The literature on employee engagement suggests how organizations and employees can reciprocally foster engagement [36] over time through two-way communications and social interactions that facilitate opportunities for making meaning [39]. Similarly, a framework on student engagement couches engagement as the "deeper reciprocity in the teaching-learning relationship where students' engagement begins as they actively construct their learning in partnership with teachers, work toward deep conceptual understanding, and contribute their own ideas to building new knowledge ..." [40]. In the field of information systems, the interplay between intrinsic and extrinsic factors characterize transitions through each stage of the engagement process. As an example, factors that drive the point of engagement include the aesthetic appeal of the technology in combination with users' intrinsic motivations and interests in the technology as well as their perception that they have sufficient time to use it.

As a dynamic and relational process, the engagement process has been described as cyclical "feedback loops over time" [31], whereby relational outcomes may act as engagement antecedents at subsequent points in time. This is consistent with studies of engagement in education, where engagement has been identified as requiring connections between the different relevant parties; these relationships facilitate engagement in the education process and tasks. In particular, Bond et al. indicate in their definition of

student engagement that "the more students are engaged and empowered within their learning community, the more likely they are to channel that energy back into their learning, leading to a range of short- and long-term outcomes that can likewise further fuel engagement" [29].

4 A Final Word

Conceptually defining patient engagement in cancer research is important to deliver on its promises, which include overcoming inequities in cancer research participation [3, 41–43], developing approaches that meet patients' needs and "end cancer as we know it" [44], and, more generally, promoting value-based healthcare [45, 46]. The broader body of literature on patient engagement frequently uses the word engagement synonymously with involvement or participation in research [47–49]. Longstanding frameworks such as the International Association's Public Participation (IAP2) Spectrum [50] refer to participation occurring along a continuum from passive to active roles [48, 49, 51, 52]. These frameworks have been applied to a range of healthcare activities, including research, direct clinical care, organizational decision making, and policy making. Across different languages, nuances may be less apparent in the meaning of terms such as engagement, involvement, and participation [52], however in some international settings, the differences are made quite explicit [53].

Conceptualizations of engagement from diverse academic disciplines indicate that the phenomenon of patient engagement in cancer research be conceptualized as a state and as a process. Patients interact with research in different capacities (e.g., as partners on the study team or as study participants). As a state, patients' make cognitive, emotional, and behavioral investments by virtue of their intrinsic motivations to engage [32] and their research-related interactions, including fair compensation, or the lack thereof, for their contributions [54, 55]. As a process, patients' engagement necessarily ebbs and flows as they move through different activities of the research lifecycle and as cancer researchers seek to foster patients' overall engagement for different durations (e.g., 30 min to participate in remote-based cancer genomics research [56]; 5 years to participate in a longitudinal cancer treatment study [57]; or ongoing as a patient partner on a study team [58]) to achieve particular outcomes. Arguably, the current literature encompasses only a fragmented vision of this phenomenon.

These insights highlight the urgency to develop a more complete understanding of patient engagement in cancer research. Future work needs to operationally define patient engagement in cancer research, which will entail identifying the characteristics that comprise engaging experiences and will facilitate the development of patient engagement

measures. This work is essential to advancing the study of patient engagement in cancer research and determining if the approaches we design are in fact engaging.

Declarations

Conflict of interest Anne L.R. Schuster and John F.P. Bridges declare they have no conflicts of interest. Electra Paskett has received grants, paid to the institution, from Merck Foundation, Pfizer, and Genentech for work outside this project. Heather Hampel is on the scientific advisory boards for Genome Medical, Invitae Genetics, and Promega; is a consultant for 23andMe, AIM Specialty Health, and GI OnDemand; and has stock/stock options in GI OnDemand and Genome Medical.

Author contributions All authors contributed to the conception of this commentary. Material preparation, literature review, and synthesis were performed by ALRS, who also wrote the first draft of the manuscript. All authors commented on previous versions of the manuscript, and read and approved the final version.

Funding This work was funded by the Ohio State University Comprehensive Cancer Center, and in part from a Grant from the National Cancer Institute (U24 CA252977-01).

Open Access This article is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License, which permits any non-commercial use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc/4.0/>.

References

1. Cancer Moonshot Research Initiatives: Establish a Network for Direct Patient Engagement. <https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/implementation/patient-engagement>.
2. Sharpless NE, Singer DS. Progress and potential: the cancer moonshot. *Cancer Cell*. 2021;39(7):889–94.
3. National Cancer Institute. Cancer Moonshot. Blue Ribbon Panel Report 2016. 7 Sep 2016
4. Pitts PJ. Towards meaningful engagement for the patient voice. *Patient Patient Centered Outcomes Res*. 2019;12(4):361–3.
5. Pitts PJ. The patient voice: at the intersection of a us regulatory revolution. *Patient Patient Centered Outcomes Res*. 2016;9(5):373–7.
6. Bridges JFP, Loukanova S, Carrera P. Patient empowerment in health care. In: Heggenhougen HK, editor. *International encyclopedia of public health*. Oxford: Academic Press; 2008. p. 17–28.
7. Deverka PA, Bangs R, Kreizenbeck K, Delaney DM, Hershman DL, Blanke CD, et al. A new framework for patient engagement in cancer clinical trials cooperative group studies. *J Natl Cancer Inst*. 2018;110(6):553–9.
8. Loukanova S, Molnar R, Bridges JF. Promoting patient empowerment in the healthcare system: highlighting the need for patient-centered drug policy. *Expert Rev Pharmacoecon Outcomes Res*. 2007;7(3):281–9.
9. Canadian Institutes of Health Research. Strategy for Patient-Oriented Research. <https://cihr-irsc.gc.ca/e/41204.html>.
10. Patient Centered Outcomes Research Institute (PCORI). Science of Engagement PCORI Funding Announcement. <https://www.pcori.org/funding-opportunities/announcement/science-engagement-pcori-funding-announcement>.
11. Lough S. Need to define patient engagement in research. *CMAJ*. 2015;187(12):E385–6.
12. Patient Focused Medicine. Making systematic patient engagement a reality. <https://patientfocusedmedicine.org/>.
13. Patient Focused Medicine. Framework for Patient Engagement. <https://patientfocusedmedicine.org/framework-for-patient-engagement/>.
14. Fergusson D, Monfaredi Z, Pussegoda K, Garritty C, Lyddiatt A, Shea B, et al. The prevalence of patient engagement in published trials: a systematic review. *Res Involv Engagem*. 2018;4(1):17.
15. Rebbeck TR, Bridges JFP, Mack JW, Gray SW, Trent JM, George S, et al. A framework for promoting diversity, equity, and inclusion in genetics and genomics research. *JAMA Health Forum*. 2022;3(4): e220603.
16. Oxford English Dictionary. Oxford University Press; 2022. engagement, n. 1.
17. Bryson C, Hand L. The role of engagement in inspiring teaching and learning. *Innov Educ Teach Int*. 2007;44(4):349–62.
18. Huo YJ, Binning KR, Molina LE. Testing an integrative model of respect: implications for social engagement and well-being. *Pers Soc Psychol Bull*. 2010;36(2):200–12.
19. Biljana J, Linda DH, Ana I, Roderick JB. Customer engagement: conceptual domain, fundamental propositions, and implications for research. *J Serv Res*. 2011;14(3):252–71.
20. Obilo OO, Chefor E, Saleh A. Revisiting the consumer brand engagement concept. *J Bus Res*. 2021;126:634–43.
21. Hollebeek LD, Srivastava RK, Chen T. S-D logic-informed customer engagement: integrative framework, revised fundamental propositions, and application to CRM. *J Acad Mark Sci*. 2019;47(1):161–85.
22. Appleton JJ, Christenson SL, Furlong MJ. Student engagement with school: critical conceptual and methodological issues of the construct. *Psychol Sch*. 2008;45(5):369–86.
23. Fredricks JA, Blumenfeld PC, Paris AH. School engagement: potential of the concept, state of the evidence. *Rev Educ Res*. 2004;74(1):59–109.
24. Nguyen TD, Cannata M, Miller J. Understanding student behavioral engagement: importance of student interaction with peers and teachers. *J Educ Res*. 2018;111(2):163–74.
25. O'Brien HL, Toms EG. What is user engagement? A conceptual framework for defining user engagement with technology. *J Am Soc Inform Sci Technol*. 2008;59(6):938–55.
26. Kappelman LA. Measuring user involvement: A diffusion of innovation perspective. *ACM SIGMIS Database DATABASE Adv Inf Syst*. 1995;26(2–3):65–86.
27. Bailey CMA, Alfes K, Fletcher L, Robinson D, Holmes J, Buzzeo J, Currie G. Evaluating the evidence on employee engagement and its potential benefits to NHS staff: a narrative synthesis of the literature. Southampton: National Library of Medicine; 2015.
28. Kelders SM, van Zyl LE, Ludden GDS. The concept and components of engagement in different domains applied to eHealth: a systematic scoping review. *Front Psychol*. 2020;11:926.
29. Bond M, Buntins K, Bedenlier S, Zawacki-Richter O, Kerres M. Mapping research in student engagement and educational technology in higher education: a systematic evidence map. *Int J Educ Technol High Educ*. 2020;17:1–30.

30. Appleton JJ, Christenson SL, Kim D, Reschly AL. Measuring cognitive and psychological engagement: validation of the student engagement instrument. *J Sch Psychol.* 2006;44(5):427–45.
31. Brodie RJ, Hollebeek LD, Jurić B, Ilić A. Customer engagement: Conceptual domain, fundamental propositions, and implications for research. *J Serv Res.* 2011;14(3):252–71.
32. Kahn WA. Psychological conditions of personal engagement and disengagement at work. *Acad Manag J.* 1990;33(4):692–724.
33. O'Brien HL, Toms EG. The development and evaluation of a survey to measure user engagement. *J Am Soc Inform Sci Technol.* 2010;61(1):50–69.
34. Bowden JL-H. The process of customer engagement: a conceptual framework. *J Mark Theory Pract.* 2009;17(1):63–74.
35. Eigenraam AW, Eelen J, van Lin A, Verlegh PWJ. A consumer-based taxonomy of digital customer engagement practices. *J Interact Mark.* 2018;44:102–21.
36. Harter JK, Schmidt FL, Hayes TL. Business-unit-level relationship between employee satisfaction, employee engagement, and business outcomes: a meta-analysis. *J Appl Psychol.* 2002;87(2):268.
37. Brodie RJ, Ilic A, Juric B, Hollebeek L. Consumer engagement in a virtual brand community: an exploratory analysis. *J Bus Res.* 2013;66(1):105–14.
38. Nolan T, Brizland R, Macaulay L. Individual trust and development of online business communities. *Inf Technol People.* 2007;20:53–71.
39. Reissner S, Pagan V. Generating employee engagement in a public-private partnership: management communication activities and employee experiences. *Int J Hum Resour Manag.* 2013;24:2741–59.
40. Willms J, Friesen S, Milton P. What did you do in school today? Transforming Classrooms through Social, Academic, and Intellectual Engagement (First National Report). Online Submission. 2009. <https://files.eric.ed.gov/fulltext/ED506503.pdf>.
41. Lee W, Wang Z, Saffern M, Jun T, Huang KL. Genomic and molecular features distinguish young adult cancer from later-onset cancer. *Cell Rep.* 2021;37(7): 110005.
42. Stein JN, Charlot M, Cykert S. Building toward antiracist cancer research and practice: the case of precision medicine. *JCO Oncol Pract.* 2021;17(5):273–7.
43. Spratt DE, Chan T, Waldron L, Speers C, Feng FY, Ogunwobi OO, et al. Racial/ethnic disparities in genomic sequencing. *JAMA Oncol.* 2016;2(8):1070–4.
44. Fact Sheet: White House Announces Initial Steps for Reignited Cancer Moonshot [press release]. 2022.
45. Catalyst N. What is value-based healthcare? *NEJM Catal.* 2017;3(1). <https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0558>
46. Pitts P. Can there be value-based medicine without ... values? *J Commer Biotechnol.* 2018;23(4):6–8.
47. Hemphill R, Forsythe LP, Heckert AL, Amolegbe A, Maurer M, Carman KL, et al. What motivates patients and caregivers to engage in health research and how engagement affects their lives: qualitative survey findings. *Health Expect.* 2020;23(2):328–36.
48. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res.* 2014;14(1):89.
49. Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, Wang Z, Elraiyah TA, Nabhan M, et al. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expect.* 2015;18(5):1151–66.
50. IAP2. IAP2 Spectrum. https://iap2canada.ca/resources/Documents/IAP2%20Canada-Foundations-Spectrum_revised_june_orange.pdf.
51. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff.* 2013;32(2):223–31.
52. Biddle MSY, Gibson A, Evans D. Attitudes and approaches to patient and public involvement across Europe: a systematic review. *Health Soc Care Community.* 2021;29(1):18–27.
53. Cancer Research UK. Patient Involvement toolkit for researchers. <https://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers>.
54. May C, Montori V, Mair F. We need minimally disruptive medicine. *Br Med J.* 2009;339(7719):485.
55. PCORI. Compensation Framework. <https://www.pcori.org/document/compensation-framework>.
56. Count Me In. <https://joincountmein.org/>.
57. Cancer Moonshot Biobank. <https://moonshotbiobank.cancer.gov/>.
58. Anampa-Guzmán A, Freeman-Daily J, Fisch M, Lou E, Pennell NA, Painter CA, et al. The rise of the expert patient in cancer: from backseat passenger to co-navigator. *JCO Oncol Pract.* 2022;18(8):578–83.