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Measuring Consumer Engagement: A Review of Tools and Findings

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As the U.S. healthcare policy and delivery systems undergo significant reforms, initiatives are underway to increase consumers' involvement in those systems. Consumer engagement (CE) can take multiple forms: from actively engaging individuals in their own care management to involvement in large-scale organizational or policy changes.¹ Consumer engagement has the potential to assist in the pursuit of the Triple Aim: improved care experience, improved population health, and reduced healthcare costs.² Without effective measurement of CE, however, it is difficult to gauge its impact on those outcomes. In this article, we review existing CE measurement tools and evidence of its impact on patient, system, and policy outcomes and identify remaining gaps.

Introduction

The Evolving Field of Consumer Engagement

Within health reform, CE has become a policy priority. The 2010 Affordable Care Act (ACA) promotes the creation of healthcare models that engage consumers in their care, with a special focus on the use of patient-centered measures in the assessment of quality—including measures of patient experience, satisfaction, and patient-centered care (PCC).³ One of the six priorities of the Agency for Healthcare Research and Quality's (AHRQ's) National Quality Strategy is "Ensuring that each person and family is engaged as partners in their care."⁴ Consumer engagement is incorporated into national healthcare transformation projects, including several at the Centers for Medicare and Medicaid Services (CMS) Innovation Center authorized by the ACA, such as the Partnership for Patients

Abstract: Consumer engagement is increasingly emphasized in healthcare initiatives and has been a priority in healthcare reforms. Consumer engagement takes multiple forms, including increased involvement of consumers in their own care, in organizational design, and in broader policy decision-making processes. Determining the effectiveness of such involvement requires both effective measurement and empirical study, both of which have yet to be standardized or fully explored. In this review, we examine both existing measurement tools for consumer engagement and current empirical knowledge regarding the outcomes associated with each of three levels of consumer engagement. Although measurement and results at the level of direct care are more established, measurement of consumer engagement, let alone its effects at the organizational design or policy level, is less well developed. Building on our review, we make suggestions for how to fill the current gaps in understanding the measurement and outcomes of consumer engagement.

Initiative,⁵ the Comprehensive Primary Care Initiative,⁶ the Medicare-Medicaid Financial Alignment Initiative,⁷ and the Pioneer Accountable Care Organization (ACO) Program.⁸ These programs expand and build on the role of consumers beyond their involvement as partners in improved disease self-management to one in which hospitals and practices are required to actively engage consumers in program and policy development. These newer requirements that CE be integrated not only at the direct patient care but also at the organizational and policy-making levels are key; the healthcare system has not always been receptive to consumers in advisory roles, to some degree because of provider perceptions that consumers have limited capacity for such a role. This combination of required consumer involvement and systemic reluctance created a risk that their consumers' involvement would be only be token.⁹ However, as healthcare is

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ultimately “coproduced” through the interactions between professionals and consumers, including both parties in its design, as well as policymaking, may help to improve it.¹⁰

In discussing a complex construct like CE, a good set of definitions is helpful. The multidimensional framework for patient and family engagement presented by Carman et al¹ breaks CE activities across three levels: (1) direct care, such as involvement in the individual’s own treatment; (2) organizational design and governance, such as involvement in providers’ quality improvement efforts or committee participation; and (3) policymaking, such as incorporating information from or representation by consumers into public agency decision making. Crosscutting these levels is a continuum ranging from simple consultation of consumers to partnerships and shared leadership. One of the more widely used innovations is the Consumer Advisory Committee (CAC)—otherwise known as a Consumer Advisory Board (CAB) or Patient and Family Advisory Council (PFAC). These councils—which exemplify partnership at the organizational level—bring together groups of consumers (e.g., patients, family members, caregivers) to offer feedback and input on organizational decisions; the role of a CAC in an organization may vary from advisory to collaborative. According to Herrin et al,¹¹ more than 38% of hospitals responding to a national survey had a CAC.

As CE has grown in priority, there has been greater interest in systematically measuring its scope of activities and impacts. To help advance the measurement of CE, we provide a sampling of tools available for assessing direct care CE, followed by a review of available measures for CE in organizational design and governance and policymaking. Where CE outcomes exist across any of the three levels, we summarize key findings.

Methods

Using the Carman et al CE framework,¹ we conducted a review of PubMed, Google, and Google Scholar to search for English-language studies, articles, or reports that

discussed or described measurement and outcomes associated with CE at all three levels. We also tracked references from those articles to locate additional relevant studies. After an initial search that encompassed any effort to measure or describe CE, we used criteria (e.g., inclusion of tools, type of CE outcome) to select articles; each brings a unique contribution to the overall measurement of CE and its impact. In addition to direct measures of CE, we have included indirect measures and those that include aspects or items applicable to CE. A complete description of our search methodology is available as Supplemental Digital Content 1 (see Appendix, <http://links.lww.com/JHQ/A45>). Because this study relied exclusively on published secondary data, institutional review board approval was not required.

Results

Consumer Engagement at the Direct Care Level

The continuum of CE at the level of direct care includes patients being given information, being asked about their treatment preferences, and at the most integrated point, those preferences playing a role in treatment decisions.¹ Many measures at this level focus on PCC models in which patients and their families are supplied with information and participate in care decisions. Some have described this as care that is done “with” the patient and not “for” the patient.¹² These models may be assessed from the provider or patient perspective.

Approaches to Measurement. Numerous measures at this level focus on patient satisfaction under the rubric of PCC. One such widely used survey is the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), which assesses consumers’ experiences and satisfaction with their hospital’s care.¹³ Additional details on this and selected other measures of CE are shown in Table 1. Now in use by 3,500 hospitals, HCAHPS results

Table 1. Measures for Consumer Engagement and Related Topics

Measure	Level(s), purpose	Intended audience; response type(s)
Hospital Consumer Assessment of Healthcare Providers and Systems ¹³	Direct care, consumer experiences and experience with hospital care	Patients; multiple choice, 27 items
Medical Home Index: Adult ¹⁵	Primarily direct care, does include some organizational design material; assess organization's level of each domain	Self-assessment; four levels of statements to be marked as "partial" or "complete" within themes in six domains: organizational capacity, chronic condition management, care coordination, community outreach, data management, quality improvement/change
Initial Hospital Self-Assessment ¹⁶	Primarily direct care, does include some organizational design and policymaking content	Self-assessment; can be Likert-type or checklist
Is it Medical Home Care Coordination? A Checklist ¹⁷	Direct care, care coordination in medical home settings	Self-assessment; checklist of statements to be marked as "no," "partially," or "yes"
Patient Activation Measure ¹⁸ Self-Efficacy for Managing Chronic Disease ²⁰	Direct care, patient activation Direct care, self-efficacy	Patients; Likert-type Patients; Likert-type
Getting it Right: A Self-Assessment Tool for Consumer Advisory Boards ³⁰	Organizational design, board structure, recruitment, functioning, and effectiveness	Board members, staff; self-assessment; Open-ended, yes/no, and 0–3 scale ratings of how well the group performs on some items
Consumer Engagement Survey ³¹	Organizational design, most items project-specific but some more general	Consumers; Open-ended and multiple choice
Coalition Web-Based Self-Report Questionnaire ³²	Policymaking, developed for community coalitions in a prevention program focused on adolescent problem behavior	Community coalition members; Likert-type and yes/no, including multiple domains
Partnership Evaluation Levels and Measures (Appendix B) ³³	Organizational design or policymaking, suggestions for how to evaluate public–private partnerships	Target audiences and measure types would vary by level and outcome: Level 1—partnership infrastructure, function, and processes (short term); Level 2—partnership programs and interventions (short and intermediate term); Level 3—health and systems change outcomes (long term)

(Continued)

Table 1. (Continued)

Measure	Level(s), purpose	Intended audience; response type(s)
<i>Toolkits</i>		
Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups, and Communities ⁴¹	Organizational design toolkit, includes suggestions for measurement	No specific measure, but provides an overview of assessment techniques such as surveys and focus groups
Institute for Patient- and Family-Centered Care Free Downloads: Tools/Checklists ⁴²	Organizational design and direct care, includes tools for measurement	Checklists and self-assessment measures, includes Initial Hospital Self-Assessment (see measure above) and Checklist for Attitudes About Patients and Families as Advisors
Americans for Quality Health Care Quality Tool Box ⁴³	Organizational design toolkit, includes Consumer Engagement survey (see above)	Survey; many items are specific to the project but could be used as a model
Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices ⁴⁴	Organizational design toolkit, includes suggestions for measurement tools	Suggests several existing assessments such as IPFCC's checklists, Medical Home Index
Guide for Developing a Community-Based Patient Safety Advisory Council ³⁴	Organizational design toolkit, includes suggestions for measurement and evaluation	Measurement suggestions for each step are included, such as surveys pre/postimplementing a new project

are part of the criteria for CMS' Hospital Value-Based Purchasing program, which uses a Medicare payment structure to reward hospitals for the quality of care they provide.¹⁴ Consequently, measurement of consumer satisfaction now plays an integral role in the American healthcare system, and hospitals are incentivized to improve their performance. Although changes in satisfaction are not direct evidence of successfully implemented PCC, they may be affected by PCC efforts.

Other measures pertaining to PCC take the form of self-assessments that can be completed by hospital staff. The Medical Home Index: Adult¹⁵ is one such measure. Domains covered include patient/family feedback and patient/family involvement. Similarly, the Initial Hospital Self-Assessment¹⁶ is a tool that incorporates multiple levels of patient involvement, including specific attention to patient/family partnership in safety, quality, and governance, and largely focuses on the direct care experience. Other tools focus more exclu-

sively on direct care, such as the checklist measure for medical home care coordination from McAllister et al,¹⁷ which assesses several characteristics or practices of PCC.

Some direct care measures also include ways to assess patients' engagement and knowledge of their care. One example is the Patient Activation Measure.¹⁸ Patient activation, a concept associated with lower costs and better outcomes, incorporates metrics such as patients taking an active role in their care, having the knowledge and confidence to affect their health, and taking and maintaining actions to affect their health.¹⁹ Other measures focus on specific domains of patients' ability to participate in their own care, such as the Self-Efficacy for Managing Chronic Disease Scale, which measures patient self-efficacy of self-management and outcomes.²⁰

Outcomes Associated With Consumer Engagement. Multiple studies have established the benefits of CE on direct care outcomes. Patient-centered care has

been associated with increased patient satisfaction,²¹ with fewer specialty care visits, hospitalizations, and laboratory and diagnostic tests.²² Shared decision making, in which patients and providers work together to make treatment decisions, has demonstrated improvements in patients' satisfaction with treatment and confidence that they have made the right decisions.^{23,24} Care participation by hospitalized patients has also been associated with fewer adverse events.²⁵ Patients with lower levels of engagement incur greater costs than those who are more involved in their care.¹⁹ Furthermore, enhanced support for shared decision making has been associated with lower costs and fewer hospital admissions.²⁶

As these examples demonstrate, measures of CE and outcomes at the direct care level are widely available. Some of these measures of PCC also assess portions of the next level of engagement, organizational design, and governance.

Consumer Engagement in Organizational Design and Governance

At the organizational level, the continuum of engagement ranges from asking for input (e.g., patient surveys), to involving patients as advisors or council members, to patients taking on leadership roles in safety and quality improvement committees.¹ Some healthcare organizations, including health plans, provider groups, and hospitals, have created CACs that are entirely composed of patients, caregivers, and other community members. Multiple organizations, including both government agencies and consumer advocacy nonprofits, have sought to support the establishment of these CACs by offering technical assistance and resources such as toolkits (Table 1). The ways CACs are established and their impact on an organization vary because they may or may not have a direct role in system governance.

Approaches to Measurement. Empirical research on CACs and their impact has, so far, been limited. Some researchers have evaluated the process of CAC

implementation, recruitment, and representativeness; however, these efforts have not yet yielded standardized instruments. Halm et al²⁷ provided a detailed description of recruitment strategies for a hospital-based PFAC, including nominations by staff and selection from patient lists. Members were selected to ensure representation for all types of diagnoses. Conway et al²⁸ compared board and community demographic information, healthcare seeking habits, and health concerns to determine if district health board members were representative of their communities; they found that although priorities were similarly rated by members and the community, the community differed in terms of healthcare behavior and socio-demographic indicators. Similarly, Wright²⁹ examined the extent to which CAB members resembled the patient population and found that most members were not representative, with significant differences in socioeconomic status. A lack of representativeness could mean that the concerns of underserved portions of the community will not be addressed as well as if individuals from those groups were included.

Rennis and Scruggs³⁰ developed a self-assessment tool that assesses the strength of structures supporting consumer participation in councils and provides an in-depth way to measure CAB recruitment and composition. The degree to which the board is representative is addressed; however, self-assessment of composition is likely to be subject to bias. Specifically, members may not be aware if there are important voices or subgroups within their community who are not represented on the board, or be able to accurately assess whether or not the socioeconomic status of board members is representative of the community at large.

Some measures of CE focused on the direct care level also include relevant items for the organizational level (Table 1). Other measurements may be used in the council context, such as a CE survey from the Aligning Forces for Quality project³¹ which included sections on

orientation, support, meaningful engagement, and participants' experience. Other types of community involvement measurement tools could also be useful for measuring councils, such as that analyzed by Feinberg et al³² who validated a community coalition process questionnaire (Table 1). Butterfoss³³ presented a comprehensive approach for participatory evaluation of public-private partnerships, laying out multiple levels of analysis and specific domains within each that could be examined (Table 1). At the first level, partnership infrastructure, function, and processes, Butterfoss³³ describes key points to consider in the makeup and process of such groups, including recruitment, representativeness, participation, perceived effectiveness, leadership, conflict, and decision making. Measures of outcomes and longer-term impacts are also considered.

Some CAC guides and toolkits also discuss measurement. The guide produced by AHRQ³⁴ includes suggested strategies, such as surveying patient and employee satisfaction before and after initiating a new safety project. The Institute for Patient- and Family-Centered Care (IPFCC) has produced self-assessment measures, including an attitude checklist for staff that assesses their opinions and feelings about having patients as advisors.³⁵ However, if councils are as prevalent as the Herrin et al¹¹ survey of hospitals suggests, a formal CAC measurement tool that integrates multiple domains and perspectives (e.g., consumers, staff) would likely be beneficial.

Outcomes Associated With Consumer Engagement. Much of what we know about the effects of CACs at this time is derived from case study reports of individual organizations. The Dana-Farber Cancer Institute³⁶ released a report listing the accomplishments of their adult and pediatric cancer PFACs, which included providing input on the institute's PCC policies and participating in institutional committees. The Maine Quality Counts³⁷ CAC listed its first year accomplishments, including providing

advice on implementation of Maine's Patient-Centered Medical Home Pilot. Halm et al²⁷ collected baseline data before launching a hospital PFAC. At the end of their second year, they assessed the projects that the council had pursued including providing input on the hospital's PCC policies and creating a patient handout of online resources.

Barnes and Wistow³⁸ interviewed mental healthcare user council members and providers to obtain their views on their council. Feedback differed by respondent group: both council members and providers viewed councils as beneficial because they gave users a voice, but providers were concerned that the council would allow for "extreme voices" to have a say, whereas members reported resistance to change on the part of providers and a lack of effective means to translate council suggestions into action.

Case studies of council process, composition, and outcomes shed light on their impact, but few use formal measurement tools. Such tools might also be a good basis on which to build better CE measurement in policymaking.

Consumer Engagement at the Policymaking Level

At the level of policymaking, the continuum of CE includes public agencies soliciting community opinions to help inform funding priorities, as well as committing to patients having equal representation on committees that make those decisions. Some groups, such as the federal Health Information Technology Policy Committee, include designated board seats for consumers. However, this kind of dedicated representation at the policy level is relatively uncommon.¹ The result of this scarcity of representation is that CE in this arena is both underutilized and understudied.

Approaches to Measurement. Although measures are more challenging to find, case studies and organizational measures might provide a starting point. Thus far, most measures applicable to policymaking are

designed for use in the hospital environment. Some hospitals, health plans, and providers include designated seats for consumers on internal committees and boards, making this a good place to start an examination of formal roles for consumers in policymaking. The Medical Home Index¹⁵ and IPFCC's self-assessments include items about the integration of consumers and their feedback into hospital policymaking. Some of the measurement suggestions made in the AHRQ guide could be modified for the policy level, such as evaluation forms completed by meeting attendees, perhaps including information on consumers' engagement in policy decisions.

Other examinations of community partnerships could make contributions to measurement in the policy arena. Feinberg et al³² conducted a survey of community coalition members incorporating scales that assessed the functioning of the boards (Table 1). Their measurement model could be applied to hospitals, health plans, and provider boards that contain mixtures of community members and staff, as well as to federal, state, and local governmental committees that include community participants.

Outcomes Associated With Consumer Engagement. Most of the identified research were limited to case studies and did not include specific outcomes. For example, a literature review³⁹ found that involving patients in healthcare planning and development seemed to have produced some contributions to policy changes for those services, but information on patients' impact was limited.

Limitations

As a report assessing available literature on measures and outcomes, this study is inherently limited by the availability of that literature and its online indexing. Although we systematically sought relevant works, it is conceivable that some items have been missed, particularly in the gray literature, which is not always indexed. An area that this study did not fully encompass is literature on measures that specifically

assess the skill, receptivity, and effectiveness of provider-driven CE efforts at the organizational and policy levels. Although we acknowledge that there is value to cataloging measurement from both the consumer and the provider perspective, this study was focused on the former.

Discussion

We reviewed measurement tools that offer theoretical and practical frameworks for capturing CE activities and impacts at the levels of direct care, organizational design and governance, and policymaking. Through this review, we identified gaps that remain in both measurement and empirical understanding of the process and results of such engagement efforts. Most measurement tools focus on the direct patient care level. As one moves toward the macrolevel, measurement tools and associated outcomes become more scarce, although the literature shows a growing appreciation for these activities in published case studies and reviews, with qualitative data pointing to some short-term results. Across all levels, there is a need for additional documentation of their impact, particularly of improvements in the Triple Aims.

Conclusions

We have offered resources for those seeking to establish or evaluate CE efforts, suggesting where existing tools or frameworks could be modified to fill gaps in current measurement. Overall, measurement and outcomes for the policy level remain less developed than for CE in organizational design, which in turn is less developed than for the direct care level of CE. Positive outcomes of CE at the direct care level speak to the potential value of involving consumers in decision making at higher levels, where they might assist providers, hospitals, and plans in their pursuit of improved experience, improved outcomes, and reduced costs.

Implications

The existing evidence at the direct care level also points to the importance of

furthering the field of CE measurement and outcomes research. However, we need to be mindful in balancing depth with the potential for data collection that burdens consumers whose appointment is usually voluntary. Sites already face a variety of barriers in recruitment and retention, and thus, measures need not be another obstacle.⁴⁰ As CE continues to be an important consideration across multiple levels in our changing healthcare system, the ability to assess its impact, as well as short- and longer-term patient and system outcomes will be vital.

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