



Organizational-Level Consumer Engagement: What It Takes



Because we all should have a say
in decisions that affect **our health**



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Authors

Renée Markus Hodin, Erin McGaffigan*[^], Missy Destrampe[^]
Community Catalyst/Center for Consumer Engagement in Health Innovation

Katie Green, Joshua Traylor, Clare Pierce-Wrobel, Megan Zook
Health Care Transformation Task Force

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* LeadingAge LTSS Center @UMass Boston (ltsscenter.org)

[^] Collective Insight, LLC (collectinsight.com)



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Background

Person-centered, value-driven health care delivery includes patients and families as partners in all aspects of decision-making about their health care. In practice, however, most health care delivery falls far short of achieving this goal. Yet health care systems are increasingly seeing the value in engaging patients not only in direct patient care, but to guide organizational decisions about that care. And while there is growing interest among health care organizations in taking meaningful steps to improve patient engagement, there is a knowledge gap and activation barrier to achieving this change and making sure the voice of the patient is incorporated at all levels of organizational decision-making.

The purpose of this project was to learn from organizations that have made a commitment to engaging patients and families at the organizational and system levels, recognizing that even highly committed health care organizations are at varying stages of maturity when it comes to implementing structures to actualize their goals in this area. In particular, we were interested in learning with more specificity about the engagement structures organizations have employed, what it takes for organizations to operate those structures, and what has been the impact of these structures both on the organizations and on the people and communities they serve.

Interviews were conducted with staff, patients and families at three health care organizations that have undertaken concerted efforts to meaningfully engage consumers at the system level. The resulting case studies describe the patient and family engagement strategies adopted (or in the process of being adopted) by these organizations and estimate the resources that are needed to initiate and sustain these strategies. By sharing this level of detail, the intent is to help spur broader adoption of meaningful consumer engagement strategies by other health care providers.

Terminology

This document preferentially uses the following terms as they are defined below. Where the health care organizations studied used specific terminology to describe their objectives, activities and programs, their preferred terminology is used within their respective case studies.

Patient is used as an umbrella term to represent an individual or their authorized representative – such as a parent of a minor or an adult child of an aging parent – who interacts with the health care system. A patient may also be referred to as an individual, person, consumer, member, beneficiary, caregiver or resident.

The terms **family** and **caregivers** are used in certain contexts to refer to patient-authorized individuals involved in providing care or decision-making support for a patient. Caregivers may include family members, friends, authorized representatives, community-based supporters or others authorized by the patient to support them in their care.

Patient and family engagement is the act of partnering with patients and families in defining, designing, participating in and assessing the care practices and systems that serve them to assure they are respectful of and responsive to individual patient preferences, needs and values.

Person-centered and family-centered care refer to health care planning, delivery and evaluation that sees patients, families and caregivers as equal partners in making sure care meets their goals, needs and preferences. This can also be referred to as people-centered or patient-centered care.

Patient experience is a component of health care quality that encompasses the interactions that patients have with the health care system.

Sources: CMS, Institute for Patient- and Family-Centered Care, AHRQ, National Academy of Medicine, Center for Consumer Engagement in Health Innovation, Health Care Transformation Task Force



Methods

A five-person advisory committee was convened to advise the project. Members of the advisory committee represented subject matter experts in patient/family-centered care, providers, payers, academic researchers and community/consumer representatives. Case study subjects were identified through a literature review; the advisory committee reviewed seven prospective case study subjects identified through the initial literature review and used the criteria described below to make recommendations to inform the final selection of three case study subjects. Additionally, the committee considered the geographic diversity of the organizations.

Prospective subjects were evaluated by the following criteria:

- **Maturity:** Preference for organizations with a demonstrated history of patient/family engagement activities at an organizational level and strong evidence of commitment to the long-term sustainability of these activities.
- **Population:** Preference for organizations with a focus on vulnerable populations (low-income, older adults, people with disabilities, people with multiple chronic conditions), with patient/family engagement participants who are representative of the population they serve and who receive a meaningful proportion of care/services at the organization.
- **Structures:** Preference for organizations that have invested in the creation of patient/family engagement structures that are meaningfully incorporated into organizational decision-making, governance and operation.
- **Impact:** Preference for organizations that demonstrate evidence of actions taken as a result of established patient/family engagement structures. Examples of action could include (but are not limited to) changes to care delivery processes, changes to staffing levels and training, or infrastructure improvements undertaken as a result of patient/family guidance.

The case study analysis was conducted through a review of documents provided by the study sites, key informant interviews, and an in-person site visit to understand the organization's approach to consumer engagement, including the following areas:

- a. Patient and family member engagement strategies and structures*
- b. Operational activities/steps needed to implement strategies*
- c. Key resources required to implement and operate strategies*
- d. Impact and successes of patient and family member engagement work*
- e. Challenges*
- f. Considerations when replicating/scaling activities*

Using a uniform interview guide, the researchers conducted onsite interviews with staff leading consumer engagement strategies, organizational leadership, key administrative staff, quality improvement and clinical staff, and patients participating in consumer engagement structures. In some cases, follow-up interviews were conducted by phone. The interviews were recorded and transcribed (or, when interviewees declined permission to record, detailed notes were taken) and the information was organized by the qualitative areas of study listed above for each case study and compared for similarities and differences across sites.

The approach was modified for multi-institutional organizations by conducting interviews with representatives from local systems and practice sites as well as at the corporate level. The resulting case studies are primarily



focused on comparing approaches at the local level while also detailing how the larger systems play a role in scaling patient engagement activities across sites. The study was limited in the ability to make cross-site comparisons by variations in the amount of information made available by each site to the research team, as well as the inherent structural and operational differences among children’s hospitals, community health centers and multi-state health systems.

Participating case study organizations received a modest stipend in consideration of the time and effort associated with the project and reviewed case study materials prior to publication. The research was determined to be exempt from review by the Institutional Review Board (IRB) of the University of Massachusetts Boston.

Findings

The organizations studied varied in size, structure, location, patient population, and the consumer engagement structures and mechanisms observed were similarly diverse. [Trinity Health](#), one of the nation’s largest multi-institutional Catholic health care delivery systems, operates a network of over 90 hospitals and over 100 continuing care programs serving 30 million patients across 22 states.¹ [Children’s Mercy](#) is a comprehensive pediatric medical center in Kansas City, Missouri handling 15,000 inpatient admissions and over 600,000 outpatient visits per year. And [Hudson River Health Care \(HRHCare\)](#) is a network of 43 federally-qualified health centers (FQHCs) providing access to primary and preventive care visits for low-income individuals in the Hudson Valley of New York, as well as in New York City and Long Island. The individual case studies provide additional detail about how the organizations have operationalized mechanisms and structures to support consumers; this section provides a summary of the overarching findings and lessons gleaned from the case studies.

Children’s Mercy	A comprehensive pediatric medical center with hospital campuses and satellite clinics in Missouri and Kansas providing both inpatient and outpatient services.
HRHCare	A network of community health centers in New York State providing comprehensive primary and preventive health care services to the underserved and vulnerable.
Trinity Health	A multi-institutional non-profit health system with facilities in 22 states, including hospitals, continuing care locations, senior living facilities, home & hospice services, and safety-net health centers that provide care to the un/underinsured population.

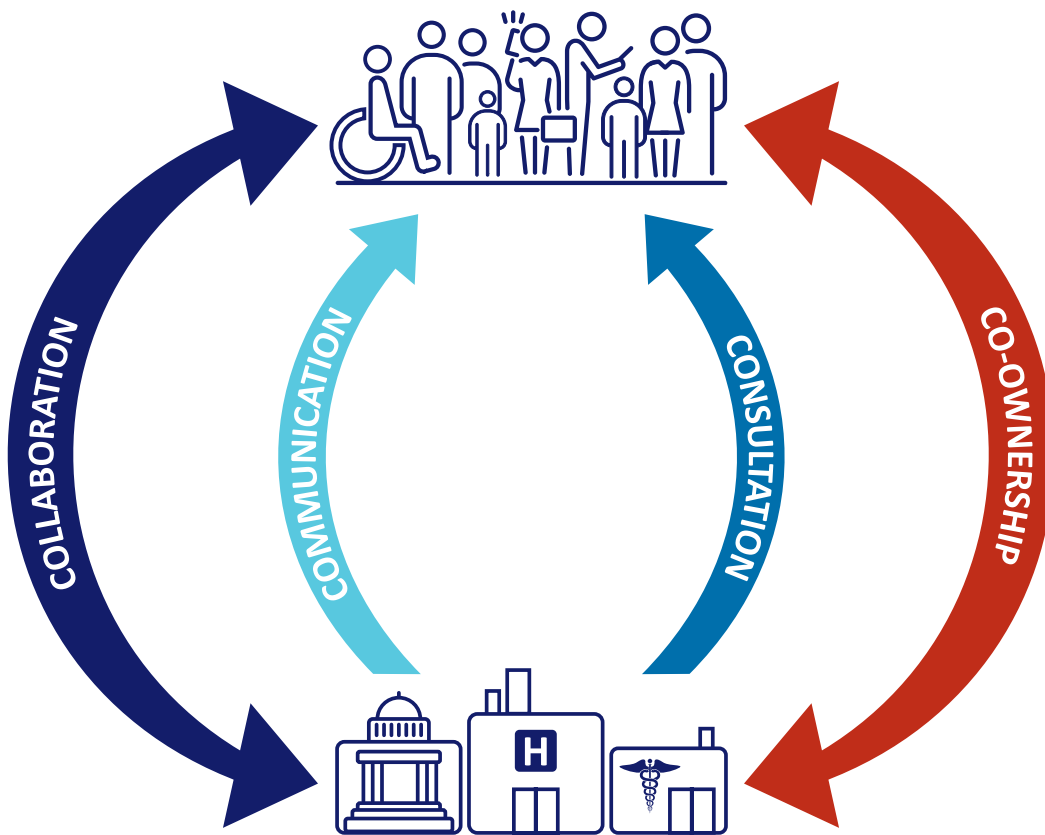
¹ For purposes of this project, we focus primarily on two Trinity Health hospitals – Saint Joseph Mercy and Saint Alphonsus – that exemplify the system’s commitment to patient and family member engagement.



a. Patient and family member engagement strategies and structures

There is a wide range of approaches to patient and family member engagement at the organizational and system levels. These approaches range from those that are more “transactional” in nature (i.e., they seek patient involvement), to those that have the potential to be “transformational” (i.e., they seek deeper patient engagement). Many organizations employ a variety of approaches in order to engage a larger and more diverse percentage of their patient and family member population.

PATIENT AND FAMILY ENGAGEMENT APPROACHES



<p>COLLABORATION <i>Organization cooperates, jointly designs and participates</i></p> <p>Examples include:</p> <ul style="list-style-type: none"> Advisory or quality improvement committees Skill-building training for patients 	<p>COMMUNICATION <i>Organization shares information</i></p> <p>Examples include:</p> <ul style="list-style-type: none"> Newsletters and ads/emails to promote services Health fairs 	<p>CONSULTATION <i>Organization seeks information</i></p> <p>Examples include:</p> <ul style="list-style-type: none"> Key informant interviews Surveys Listening sessions and Focus groups 	<p>CO-OWNERSHIP <i>Organization shares decision-making</i></p> <p>Examples include:</p> <ul style="list-style-type: none"> Strategic planning committees Governance board membership for patients
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Source: Center for Consumer Engagement in Health Innovation



Patient and family advisory councils (PFACs) are by far the most common structure by which the studied sites convene and engage a group of patients to provide feedback to the health care system on an ongoing basis. The sites all employed staff dedicated to supporting the efforts of the PFAC, which included recruiting and training PFAC members to participate in advisory councils and boards. The structure and variety of the PFACs varied by site, with some sites operating multiple patient advisory boards dedicated to specific conditions, patient populations (e.g., racial and ethnic groups), and lines of service delivery. The sites also differed in the methods for recognizing PFAC member contributions, including by providing awards or gift cards. Various feedback loops were employed to ensure that patient feedback reaches the appropriate decision-makers within the organization and, in turn, to share the results and actions generated by their feedback back with the councils, which was noted by all sites as a key contributor to PFAC member retention.

In addition to advisory councils comprised solely of patient or family participants, the sites studied also included patient and family representatives serving on other organizational governance bodies. All sites also utilized patient focus groups to gather feedback, some on a regular basis and others on an ad hoc basis related to a specific need or project. Focus groups are differentiated from patient and family advisory councils in that they seek one-way feedback and do not include the same patient participants on an ongoing basis. Similar to focus groups, some sites hosted town hall meetings to solicit community feedback and provide an opportunity for community members – who may or may not be current patients – to interface with representatives from the health system.

The case study organizations also managed structures for soliciting direct patient feedback and involvement in education and quality improvement initiatives. Some of the sites involved patients in provider training programs, such as offering “voice of the patient” sessions at new staff orientations, or opportunities for patients to provide direct feedback to employees about patient experience. All case study sites incorporated patient feedback into organizational quality and process improvement activities, though they differed in the method of collecting feedback and how directly patients were involved in the improvement process. One common area where the organizations sought patient involvement was in the development and improvement of patient-facing education and communication materials, including consumer-facing health information technology.

Separate from organizational-level patient engagement structures, the case study sites also managed various patient engagement structures to gather patient feedback related to active care relationships. The most common mechanism for gathering feedback was post hoc patient care experience surveys, though some sites utilize patient rounding programs to collect patient input concurrent with a patients’ care or hospital stay.



Person-Centered Engagement Structure	Description	Case Study Organizations Using Structure		
		Trinity Health	HRH Care	Children's Mercy
Governing Bodies (Formal Patient Participation)	Engagement structures that include patient and family representation on formal governing bodies such as a board of directors and executive level leadership meetings and extends official voting rights to patient participants.		X	
Governing Bodies (Indirect or Ad Hoc Patient Participation)	Engagement structures that incorporate patient and family member feedback into leadership and governance processes in an advisory capacity, including committee participation.	X		X
Permanent Advisory Councils	Formal bodies with bylaws, formal membership requirements, and recurring meeting schedules. These may include patient and family advisory councils (PFACs), committees for specific service areas, or groups formed to focus on specific populations or conditions.	X	X	X
Permanent Advisory Councils for Vulnerable Populations	Bodies similar in structure to the advisory councils described above and dedicated to engaging vulnerable populations including persons with disabilities, communities of color, immigrants, etc.	X	X	X
Focus Groups	Generally, ad hoc convenings intended to elicit patient and family member feedback on specific projects or issue areas.	X	X	X
Surveys	National standardized and locally-developed survey instruments to collect feedback on patient experience.	X	X	X
Experience Tracing Initiatives	Approaches such as Gemba walks and formal processes for tracking patient, family member, and staff movements/workflows within the health care system to inform quality improvement efforts.	X	X	X
Rounding	Formal process for health system staff to gather feedback specific to the quality of care and patient experience through regular inpatient visits, distinct from the clinical rounding done by medical teams.	X		X
Staff Training and Education	Structures that incorporate patient and family perspectives and feedback into staff trainings. This includes patient and family editing of training materials as well as direct experience sharing through workshops and speaking/presentation opportunities.	X	X	X



b. Operational activities/steps needed to implement strategies

The case study organizations uniformly cited leadership commitment to patient engagement as a critical factor for successfully implementing and sustaining a comprehensive, system-wide patient engagement strategy. Starting with leadership direction at the top, the organizations all explicitly included patient engagement and input as a component of operational objectives, metrics and governance. Culture change was a less tangible, but no less significant, supporting factor to realizing a patient engagement strategy, manifested by a recognizable shift in organization-wide expectations about patient engagement and shared staff understanding of its importance as a regular part of delivery system operations. The adoption of value-based payment models and care delivery redesign was a motivating factor for some organizations to change the status quo related to patient engagement.

With commitment from leadership down to front-line staff to the ideal cultural model, patient engagement structures ultimately rely on dedicated and skilled administrative personnel. In addition to key staff that manage PFACs and other structures, the studied organizations described other clinical and administrative staff that provide in-kind support to patient engagement efforts either directly or in the context of their other responsibilities, such as incorporating patient input into quality and process improvement initiatives. Health care systems with multiple hospitals and/or practice locations also dedicated resources to shared learning opportunities for patient engagement administrators. For example, the larger systems created PFAC toolkits and held monthly meetings with patient engagement staff across sites to share best practices related to person-centered engagement. From a system level, organizations sought consistency in implementing best practices across sites, while allowing some flexibility for localized approaches.

c. Key resources required to implement and operate strategies

The primary expense for health systems to operate person-centered engagement strategies is personnel costs related to patient engagement leadership and supporting staff; the seniority and number of FTEs supporting the work varied by organization.

Key Staff
<p>Staff titles for full-time staff dedicated to patient and family engagement included:</p> <ul style="list-style-type: none"> • Director of Patient and Family Engagement • Chief of Patient Experience and Staff Development/Chief Experience Officer • Program Managers for Patient and Family Engagement • Director of Person-Centered Care Experience <p>Titles for other staff responsible for integrating patient and family engagement into their broader work or overseeing the patient and family engagement team included:</p> <ul style="list-style-type: none"> • Chief Nursing Officer/Senior Director of Nursing • Medical Practice Director • Director of Quality Improvement/ Vice President of Quality Management • Assistant Vice President of Care Management • Senior Vice President of Ambulatory and Physician Practice Operations • SVP of Diversity and Inclusion



In addition to personnel costs, other direct costs primarily related to operating the PFACs, included meeting-related expenses such as travel/parking reimbursement, food and refreshments, meeting space rental, and meeting materials and training resources. All organizations established a dedicated budget for recognition gifts for patients and reimbursement for their costs such as mileage and parking. Other indirect or in-kind expenses included training costs for the patient engagement staff and other clinical/administrative staff's participation in patient engagement activities and/or response to patient input.

d. Impact of patient and family member engagement work

The case studies reveal a wide variety of outcomes from their engagement work, reflecting positive impact on both the organization and the patients and families involved in their strategies. Dukhanin, Ropazian, and DeCamp's (2018) [systematic review of metrics and evaluation tools for patient engagement](#) in health care organization- and system-level decision-making provides a typology to categorize impact metrics as process or outcomes measures, and further organized outcomes measures as internal, external or aggregate. For example, outcome measures may assess impact on the engagement participants and the services provided (internal), influence on the broader public and population health (external), or the cost-effectiveness of the engagement (aggregate).

The organizations interviewed primarily utilized internal outcomes metrics to measure the success of the patient engagement efforts, with a mix of process and outcomes measures. For example, [Children's Mercy](#) and [Trinity Health](#) members systems use as a process measure the number of patient and family advisors participating on committees and projects as one of their measures of engagement success. Outcome measures included patient and staff satisfaction with the engagement programs, the level of institutional awareness among all staff regarding person-centered engagement efforts, and changes in quality and satisfaction measures among patients impacted by the changes that were informed by the patients. A recurring theme for many organizations was including patient and family advisors in setting targets and goals for the PFAC in which they participate.

Broadly speaking, the health systems described organizational policy changes that resulted from patient feedback. One organization pointed to an improvement in patient experience with perioperative services after engaging patient and family advisors to improve how patients move through same-day surgery corridors. Changes that resulted from that engagement included changing where patients say goodbye to their loved ones prior to procedures to reduce stress on patients and families. Three areas were commonly mentioned as directly benefiting from patient community input: 1) Patient education and communication material; 2) Facility improvements; and 3) Consumer-facing health information technology. The health systems cited metrics to demonstrate that person-centered engagement has successfully impacted patient and family experience, quality of care and provider/employee morale.

One hospital in the Trinity Health system saw an increase in their patient experience ratings on standard surveys such as HCAHPS and their net promoter score, which they attributed to improved staff interaction with patients in response to engagement activities.



e. Challenges

Changing organizational culture to establish new norms around engaging patients is not easy and significantly changing the status quo does not happen overnight. The organizations also found challenges with managing the complexity of local communities and individual patient populations that have unique needs and require tailored approaches. Organizations can also struggle to engage and provide accommodations for a diverse representation of patients. This challenge can limit both the comprehensiveness of patient views represented by the feedback collected via engagement structures and the organization's progress toward reducing disparities by race or income. It can also be difficult for organizations to implement feedback loops between the patients providing input and the components of the organization implementing organizational change in response to that input. Yet, tangible demonstration of a closed feedback loop is critical for patient buy-in, so its absence can negatively impact retention. Finally, all the organizations voiced concern about the long-term sustainability of established structures as funding and budget availability can fluctuate over time.

f. Considerations when replicating/scaling activities

The three case studies offer several best practices for other organizations to consider replicating in their own person-centered engagement work.

- **Leadership Buy-In:** Organization leaders must value patient and family engagement and be willing to dedicate resources to the cause. It is also essential that responsibility for patient engagement is not siloed off from leadership within the organization. To maximize organizational buy-in, patient and family engagement staff should be visible at key meetings and in daily encounters. Some organizations may consider placing patient engagement staff offices close to those of the C-Suite leaders.
- **Dedicated Staff Resources:** Organizations should dedicate staff with primary responsibility to coordinate/oversee development and operations of the patient engagement strategy. For example, at [HRHCare](#), the Chief of Patient Experience and Staff Development not only oversees all aspects of patient engagement across the organization, but also personally participates in most, if not all, of the structures and strategies. Staff that lead PFACs or focus groups should possess strong facilitation and group management skills in order to establish a comfortable and safe environment for participants to respond with openness and honesty.
- **Dedicated Budget:** Health systems should also set a reasonable budget for expenses related to the activities described above; the individual case studies provide more detail about how to estimate those costs. At [Children's Mercy](#), for example, in addition to the allocation of staff time to facilitate and attend patient and family engagement strategies, additional costs that are incurred include food costs and accommodations, as needed (e.g., childcare, transportation, parking, printing and video conferencing).



- **Feedback Loops:** Setting clear expectations for patients, as well as the rest of the organization, about what to anticipate from engagement structures also helps to engender trust in the process. The Experience Advisor Program at a [Trinity Health](#) system serves as the first step for volunteers interested in participating in any of their engagement activities. This program gives all advisors a baseline orientation to the health system and training to support their role as advisors.
- **Recognition Programs:** Organizations should show appreciation for both for the patients who commit time to work with health systems and the providers who devote their time engaging patients to improve operations and care delivery. All three organizations featured in the case studies dedicated resources to recognizing the contributions of volunteer patient and family advisors, such as volunteer gifts, awards or celebratory materials.

These and other best practices will be included in a forthcoming change package aimed at providing a roadmap for other health care organizations interested in implementing person-centered engagement strategies in the communities they serve.