

Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care

Susan B. Frampton, PhD, Planetree; **Sara Guastello**, Planetree; **Libby Hoy**, PFCCpartners; **Mary Naylor, PhD, FAAN, RN**, University of Pennsylvania School of Nursing; **Sue Sheridan, MBA, MIM, DHL**, Patient-Centered Outcomes Research Institute; **Michelle Johnston-Fleece, MPH**, National Academy of Medicine

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ABSTRACT | Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes explicit and partnered determination of goals and care options, and it requires ongoing assessment of the care match with patient goals. This vision represents a shift in the traditional role patients and families have historically played in their own health care teams, as well as in ongoing quality improvement and care delivery efforts. PFEC also represents an important shift from focusing solely on care processes to aligning those processes to best address the health outcomes that matter to patients. In a culture of PFEC, patients are not merely subjects of their care; they are active participants whose voices are honored. Family and/or care partners are not kept an arm's length away as spectators, but participate as integral members of their loved one's care team. Individuals' (and their families') expertise about their bodies, lifestyles, and priorities is incorporated into care planning and their care experience is valued and incorporated into improvement efforts.

A prevalent and persistent challenge to a system-wide transformation to PFEC is uncertainty about whether the resource investment required will lead to better results. There is also a lack of clarity about how, practically speaking, to make it happen.

To address these barriers, the National Academy of Medicine's (NAM's) Leadership Consortium for a Value & Science-Driven Health System convened a Scientific Advisory Panel (SAP) to compile and disseminate important insights on culture change strategies. The SAP's focus was on evidence-based strategies that facilitate patient and family engagement and are tied to research findings revealing improved patient care

and outcomes. To achieve this goal, the SAP drew on both the scientific evidence and the lived experiences of patients, their care partners, practitioners, and leaders to develop a comprehensive framework that explicitly identifies specific high-impact elements necessary to create and sustain a culture of PFEC. Research in support of the various elements of the model was then compiled into a selected bibliography. This paper introduces the framework and associated evidence, along with practical examples of elements of the model applied in the "real world," with the goal of supporting action that will pave the way for PFEC to become the norm in health care.

The SAP thoroughly discussed the terminology to use within the framework, cognizant that terms such as “person-centered” and “people-centered” are increasingly used in the field. Because this paper and the guiding framework it introduces are largely focused on care delivered by health care organizations to individuals accessing the system, the authors have chosen to use the term “patient and family” engaged care, while reserving the term “person and family engagement” for other health and health care activities aimed at engaging and empowering individuals in the community and/or outside a health care setting.

Introduction

Patient and family centered care (PFCC) has been identified as a cornerstone of the national strategy for delivering better care and achieving better patient experiences at a lower cost. Until fairly recently, efforts to promote PFCC have focused primarily on changing the behaviors of patients (and, increasingly, families). These endeavors simultaneously treated patients as presenting “the problem to be fixed” while relying on them to provide insights to improve the health care delivery system via cursory efforts lacking structure. In hindsight, it is understandable that such efforts have not yet yielded widespread, sustainable transformation of our health care delivery system.

Not surprisingly, it is the long-standing work of dedicated patients, families, and patient advocacy organizations to reform our health system toward patient-centeredness that has brought clarity to what it really means to be patient and family centered. Their efforts have helped to highlight the shortcomings of token efforts toward engagement and have brought to light the discrepancies between the health outcomes prioritized by clinicians and those that matter most to patients. As a result, health care leaders are now more cognizant of their roles in driving a patient-centered culture of care that continuously integrates patient and family perspectives and involvement—at the point of care, in health care system design, and in defining outcomes that matter most. PFCC and patient and family engagement, today, both embrace partnership—working *with* patients and families, not simply doing *to* and *for* them. This fundamental shift represents, we assert, a shift to patient and family *engaged* care (PFEC).

PFEC is care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined

by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes explicit and partnered determination of goals and care options, and it requires ongoing assessment of the care match with patient goals. *See Box 1.* As a result of this new paradigm, the enormous potential to improve health and health care outcomes by actively engaging patients and families as true partners in their care and in the redesign of health care systems and processes has caught fire among practitioners, policy makers, executives, researchers, and academics. This, in turn, has accelerated the pace of inquiry and exploration into which PFEC strategies have a positive impact, what makes them effective, and what makes them sustainable.

Despite efforts to make PFEC a predominant feature in *all* health care interactions, it remains an aspirational aim. These efforts have not resulted in a comparable pace of culture change and care delivery in hospitals, physician offices, patients’ homes, and all of the contexts where patients receive care (Bernabeo and Holmboe, 2013; Herrin et al., 2016).

Despite a significant amount of scientific inquiry and emerging consensus on the resulting evidence, intrinsic value and benefits of PFEC, there is less clarity or consensus about the most effective ways to move universal adoption forward. An important barrier to more widespread adoption is the lack of a comprehensive, credible, and widely accessible evidence base for PFEC to inform change efforts. In many ways, the PFEC evidence base has been a casualty of a very narrow definition of what constitutes evidence. Knowledge derived from the traditional, biomedical research model in support of PFEC may be limited (and is growing), but it is important to consider *all* the knowledge available to us, including insights derived from the “experience base.” This base includes day-to-day problem solving in the lives of frontline clinicians and patients and families. In the current state of PFEC, we find that available research could be substantially augmented by experiential knowledge. Limiting activities that support a culture of PFEC based on reported research may significantly underestimate the knowledge available to drive change. The experiences of patients and their care partners represent a vital dimension of this emerging knowledge base. What matters most to patients concerning their health outcomes coupled with their personal care experiences and observations regarding how the health system

BOX 1 Patient and Family Engaged Care

Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes explicit and partnered determination of goals and care options, and it requires ongoing assessment of the care match with patient goals.

Adapted from Institute of Medicine, Transforming Health Care Scheduling and Access: Getting to Now, 2015.

operates are essential contributions to creating a culture of PFEC.

To realize the aspirations of PFEC as a new norm in health care, it is important to acknowledge that true transformation is not about addressing the “patient and family problem,” the “clinician problem,” the “leadership problem,” or the “payer problem.” Rather than casting these various players as the “problem,” it is crucial to understand that all of these stakeholder groups are part of the solution. The actions, behaviors, and attitudes of each of these groups (plus many more) all intersect to create the culture of health care delivery. To accelerate culture transformation, the experiences of all who interact with the health care system must guide the change. Having a framework that identifies *how* to guide and manage change of that magnitude, along with a compilation of supportive evidence, is essential. Absent a guiding framework for integrating PFEC across health care settings, PFEC continues to be a “nice to have” rather than a “must have” to achieve high-quality, safe, and efficient care.

Approach

To respond to the need for a framework that would deliver greater specificity, clarity, and direction on what it will take to make PFEC the norm in health care, the SAP for the Evidence Base on Patient and Family Engaged Care was convened under the auspices of NAM’s Leadership Consortium for a Value & Science-Driven Health System. The efforts of the SAP also were designed to support and inform the work of the Consortium’s Care Culture and Decision-Making Innovation Collaborative (CCDMIC). The SAP was empaneled to compile and disseminate important

findings and insights on culture change strategies that facilitate PFEC. In particular, the group was asked to focus on aspects of PFEC with validated results tied to better culture, better health outcomes, better care, and lower costs. This compilation would be organized into a guiding framework explicitly depicting the structure, practices, and approaches health care systems may ultimately adopt to realize the potential of PFEC to improve health and health care, support future evidence generation, and produce greater value.

Convening the Scientific Advisory Panel

Leadership for the SAP was provided by Planetree, Inc., a not-for-profit patient-centered care education, membership, and advocacy organization founded by a patient in 1978. The 25 individuals invited by the NAM to serve on the panel brought an essential mix of perspectives to the initiative. Panelists included clinical and health service researchers, health care practitioners, and patient and family leaders. Importantly, outreach efforts for panelists extended beyond the “usual suspects.” This was certainly not to devalue the important insights of familiar faces who have been advocating for PFEC change for years, but rather to make room at the table for a growing cadre of researchers who are studying the impact of often overlooked dimensions of PFEC, and whose work, when accumulated and synthesized, significantly advances the *scientifically* based case for PFEC. *See Appendix A.*

The composition and structure of this group models the nature and power of partnership at the heart of PFEC. The convergence of these various perspectives contributed significantly to the comprehensive, cumulative, and, ultimately, very practical distillation of

current knowledge and experiences into a framework for PFEC that speaks to different audiences.

From December 2015 through May 2016, the SAP worked to:

1. Identify elements and factors that consistently emerge as essential to creating and maintaining a culture of PFEC;
2. Organize those tools, strategies, and cultural elements into an easy-to-follow framework;
3. Compile evidence in support of the framework; and
4. Identify gaps in the evidence.

Each step is described in more detail below.

Identifying Common Elements and Factors for Creating and Maintaining a Culture of PFEC

This activity was kicked off with brief presentations by health care executives at three sites—an acute care hospital [1], a behavioral health hospital [2], and a federally qualified health center [3] that have successfully created and sustained a culture of PFEC. Both hospitals have been recognized with Patient-Centered Hospital Designation by Planetree and the federally qualified health center has been recognized as a Level 3 Patient-Centered Medical Home by the National Committee for Quality Assurance (NCQA). Though the organizations vary in size, services, complexity, and length of experience implementing PFEC, there nonetheless were several notable commonalities. *See Table 1.*

Creating the Framework

Recognizing the need for an easy-to-follow guide, the SAP aimed to create a framework, grounded in evidence, that would (1) identify the key cultural, structural, and programmatic elements that coalesce

to create a culture of PFEC; (2) examine the relationships between these items; and (3) clarify intended outcomes and how the various inputs drive the desired results. Development of the framework was an iterative process. The initial draft was created in consideration of the common elements and patterns for PFEC identified during the group's first call, panelists' research findings, and an informal scan of related logic models (Béliveau, 2015; Singer and Vogus, 2013). During the course of the next 4 months, the framework was refined to align with the experience, expertise, and scientific knowledge of the panelists. Final refinements were made in the publication phase in response to SAP member recommendations and patient and family feedback that the framework be graphically polished to ensure readability for numerous audiences, including patient and family partners and frontline staff.

Overview of the Guiding Framework

In effect, the group has approached the task by looking at the outcomes sought by patient and family engaged care, and then moving backward through the transformational stages to understand the related practice outputs needed, the strategic inputs to yield those elements, and the organizational foundations to craft the strategies. *Figure 1* presents the broad overview of the framework.

In *Figure 2*, the core elements of each transformational stage for patient and family engaged care are presented: the engagement outcomes of better culture, better care, better health, and lower costs; the practice outputs of better engagement, better decisions, better processes, and better experience; the strategic inputs of structures, skill and awareness

Table 1 | Summary of Common Elements and Patterns Identified for Creating and Maintaining a Culture of Patient and Family Engaged Care

Cultural Elements	Infrastructure	Practices and Tactics
<ul style="list-style-type: none"> • Investment and intentionality in creating a supportive and trusting workplace culture • Emphasis on empathy and compassion • Leadership sets the tone • Eagerness to innovate • Creation of a learning culture 	<ul style="list-style-type: none"> • PFEC fully integrated into organizational structure and strategy—not a stand-alone initiative • Structured communication channels developed to break through hierarchy and “level set” to promote partnership of all members (leaders, staff, patients, families)—coproduction, shared goals • A measurement approach that looks beyond patient experience metrics to gauge PFEC 	<ul style="list-style-type: none"> • Environmental supports to facilitate PFEC • Practices that promote patient and family engagement • Learning opportunities at every patient touchpoint



Figure 1 | Overview of Patient and Family Engaged Care: A Guiding Framework

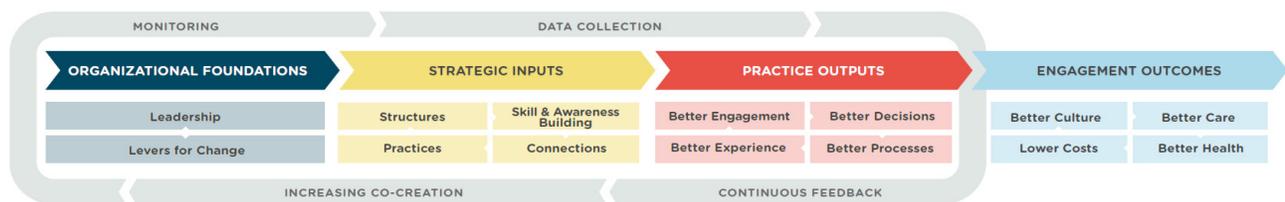


Figure 2 | Overview and core elements for Patient and Family Engaged Care: A Guiding Framework

building, connections, and practices; and the organizational foundations of leadership and levers for change.

Organized as such, the framework meets the needs of health care leaders as well as patient and family partners by demystifying PFEC, providing guidance in implementation priorities and sequencing, and, finally, illustrating why this work is worth doing by empirically tying implementation to outcomes. We expect the framework and associated bibliography will be a useful resource for both health care leaders and patient and family leaders to draw on in cultivating more effective partnerships and will serve as a tool to create greater receptivity among institutions for implementing these PFEC strategies.

Figure 3 presents a robust depiction of the framework with many of the key elements identified. Described below is a more detailed explanation of major elements of the model framework and a companion bibliography detailing select evidence for the major elements of the model is presented in Appendix B.

Outcomes

The genesis for creating the framework was a desire to examine and depict the premise that PFEC is a driver of an expanded notion of the “Quadruple Aim” of better health, better care, lower costs, and better work experience for providers of patient care (Bodenheimer and Sinsky, 2014). The SAP extended the fourth aim to be an overall culture of engagement: one in which patients and family caregivers are meaningfully and continually involved in decision making at all levels (i.e., at the personal level at the point of care, at the organizational level in system-level quality improve-

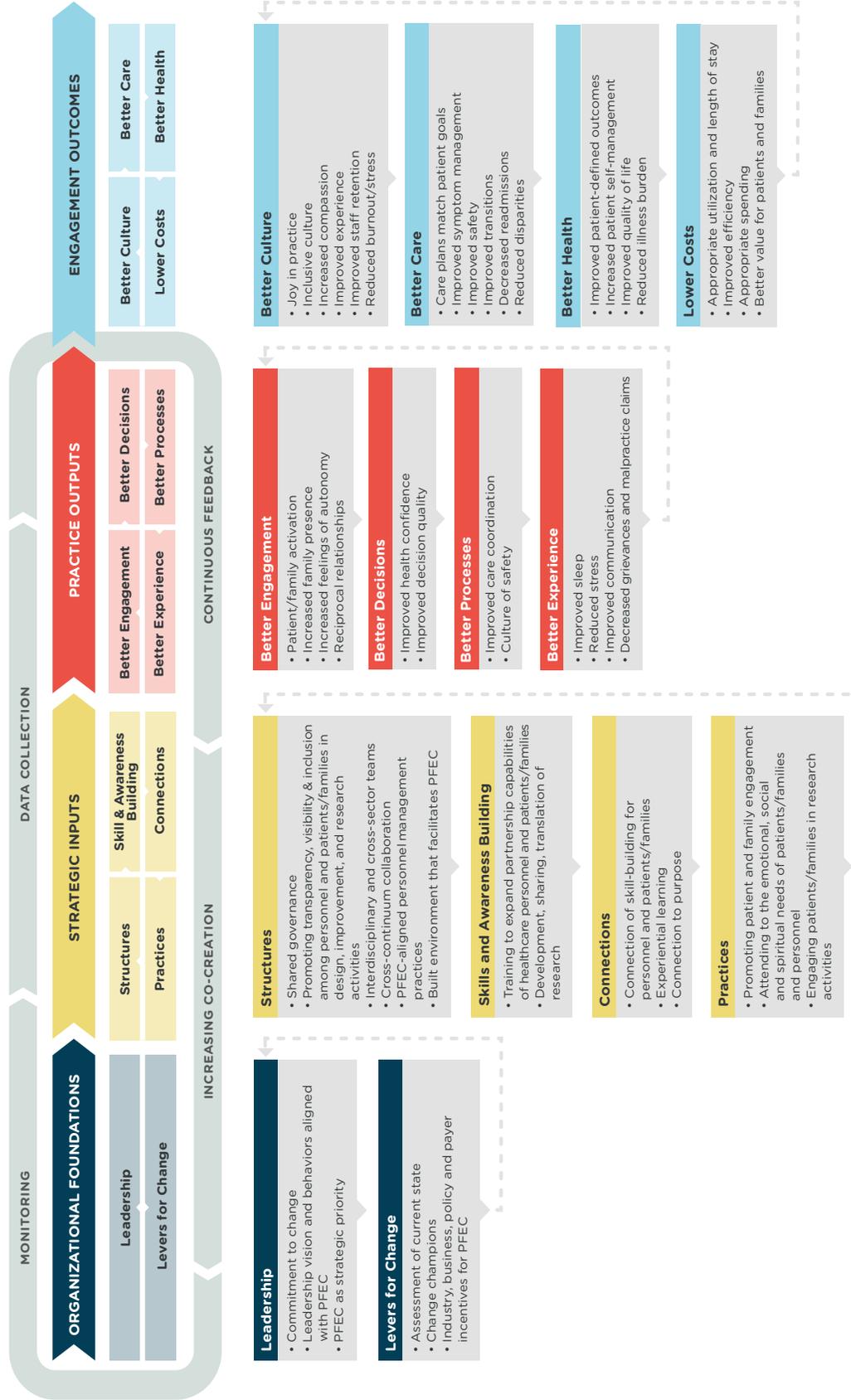
ment, and even at the macro level to guide policy development) and in which a more engaged workforce experiences greater joy in practice. All other elements of the framework drive toward this vision of a high-quality, high-value health care system. Therefore, sequentially (and logically), all elements of the framework precede the outcomes. A discussion of these desired impacts is warranted as the first point of reference, however, for reviewing the tool.

Better Culture

The inclusion of outcomes related to the experience of health care professionals underscores that organizational culture and the delivery of effective and compassionate care cannot be separated from those who are delivering that care. The prevalence of burnout and disengagement among health care professionals is not a concern peripheral to the quality of care; it is central to it (Bodenheimer and Sinsky, 2014). The interconnectedness of how PFEC touches and influences organizational culture, including the experiences of both patients and family caregivers and health care professionals, is supported by evidence tying PFEC approaches to

- Improvements in the staff experience (Atwood et al., 2016; Coulmont et al., 2013; McClelland et al., 2016),
- Improved staff retention (Coulmont et al., 2013),
- Reduction in job stress (Bosch et al., 2012), Greater satisfaction with interactions with patients (Bozic et al., 2013), Lower rates of staff burnout (Gazelle et al., 2015; Nelson et al., 2014),

Patient and Family Engaged Care A Guiding Framework



NOTE: Linear placement of each bucket is not meant to suggest order or hierarchy

Figure 3 | Patient and Family Engaged Care: A Guiding Framework

- Increased compassion (McClelland et al., 2016; Riess et al., 2012), and
- Patient satisfaction and/or perceptions of their care (Atwood et al., 2016; Coleman et al., 2015; McClelland and Vogus, 2014; McClelland et al., 2016; Nelson et al., 2014; Quan et al., 2012; Riess et al., 2011, 2012; Rosland et al., 2011; Stone, 2008; Vogus and McClelland, 2016; Williams et al., 2011; Wolff and Roter, 2008, 2011).

The true test of a culture of engagement is that opportunities to engage and influence change extend to all participants, even those who traditionally are the most difficult to reach. In a truly inclusive culture, leaders and practitioners are keenly attuned to potential social, cultural and/or linguistic barriers that may hinder engagement (among patients and families, as well as personnel), and approaches are introduced to proactively address them.

Better Care

Better care has customarily been associated with measures of patient experience, and there is a well-documented evidence base supporting that PFEC drives improvements in patient satisfaction and/or perceptions of their care as noted above.

The framework looks beyond those conventional measures to also represent emerging knowledge that supports shared decision making (Arterburn et al., 2012; El-Jawahri et al., 2010; Stacey et al., 2014) and processes for eliciting patient and family caregiver goals (Coleman and Min, 2015) as important steps toward promoting “better care,” that is, care planned, delivered, managed, and continuously improved in partnership with patients and their families in a way that integrates their preferences, values, and desired health outcomes. Drawing on this definition of PFEC, this congruence between care planning and decision making and patients’ expressed preferences, values, and goals is a critical component of what constitutes “better care.”

In addition, concepts were included to reflect that more care does not necessarily connote better care. This understanding is supported by research stressing the potential for PFEC strategies to improve transitions of care and decrease unnecessary readmissions (Greer et al., 2014; Krumholz, 2013; Veroff et al., 2013; Wennberg et al., 2010).

Finally, though perhaps implicit in the term “better care,” the inclusion of reduced disparities as an indicator here makes it explicit that better care must extend to all, regardless of race, ethnicity, socioeconomic status, insurance status, geographic location, age, education, language, health status, disability, and/or sexual orientation.

Better Health

The framework is representative of research findings that demonstrate the ability of a range of patient and family engagement strategies to yield better health as measured by improvement in clinical indicators. These include shared decision-making interventions (Wilson et al., 2010); care management support and training for family caregivers (Coleman et al., 2015; Rosland et al., 2010); and tailoring patient education to accommodate patients’ health literacy levels (Eckman et al., 2012). The potential for improving health outcomes, though, is tied not only to implementation of specific care processes and interventions, but also to how care is delivered. When care is delivered with compassion and empathy, research demonstrates that health outcomes are improved (Del Canale et al., 2012; Haslam, 2007; Hojat et al., 2011; Kelley et al., 2014; Rakel et al., 2011).

In a culture of PFEC, however, improved values on traditional clinical scales are not the only measures of better health. Also important is that individuals are able to discern progress or improvement in ways that are meaningful and personal to them, which may or may not align with traditional measures. To this end, the framework draws on evidence showing the relationship between PFEC and

- Increased patient and family success in self-management (Atwood et al., 2016; Frosch et al., 2010; Kennedy et al., 2002; Luttkik et al., 2005; Nicklett et al., 2013; Rosland et al., 2010; Stamp et al., 2016; Strom and Egede, 2012; Wilson et al., 2010)
- Improved quality of life (Frosch et al., 2010)
- Reduced illness burden (Barret et al., 2012)

Lower Costs

The guiding framework for PFEC was designed not only to guide organizational implementation efforts but also to pave the way for more widespread adoption

of PFEC cultural elements. Strengthening the business case for these elements is imperative to this latter aim. The framework draws on a growing evidence base that correlates implementation of strategies that promote patient and family engagement in their care with

- Reduced rates of hospitalization (Nelson et al., 2014; Veroff et al., 2013; Wennberg et al., 2010),
- Decreases in emergency department use (Nelson et al., 2014),
- Reduced rates of elective surgeries (Arterburn et al., 2012; Stacey et al., 2014; Veroff et al., 2013), and
- Shorter lengths of stay and cost per case (Stone, 2008)

All of these elements translate into more appropriate spending and utilization for patients, health care organizations, and payers. Within the *lower costs* realm, however, advisors acknowledged that current measures of lower health care costs reflect the system perspective but not the patient and family perspective. This was addressed by including appropriate utilization, appropriate health care spending, and better value for patients/families (defined as lower out-of-pocket costs and improved outcomes as defined by patients) as components of this domain.

Organizational Foundations

More than simply a starting point, the organizational foundations depicted in the guiding framework—leadership and levers for change—represent both internal and external contextual factors that create the necessary underpinnings for developing a culture of PFEC. They include

- An accurate assessment of the organization's current culture;
- A commitment to defined change;
- Leadership vision and behaviors aligned with PFEC;
- PFEC established as strategic priority;
- Change champions (administrative, research, clinical leader, and patient/family champions for change); and
- Industry, business, policy, and payer incentives and other facilitators that promote PFEC, including transparency of health care outcomes.

Internal Factors

The framework asserts that, without these foundational elements in place, adoption of the inputs will not have the best chance of delivering the desired outcomes. In other words, in the absence of an honest assessment of the organization's current strengths and opportunities (*see Box 2*), its goals, practices, performance, and operational realities, without a desire to create change, and without leaders on board, PFEC efforts are vulnerable to becoming an afterthought in the midst of competing priorities, or a "flavor of the month" that is abandoned when the desired results do not come quickly enough. A variety of literature shows that clearly establishing a strategic priority and having engaged leadership whose behaviors, decisions, and allocation of resources signal their level of commitment creates fertile ground where implementation efforts are positioned for success and sustainability (Avolio and Patterson, 2014; Balogun, 2003; Balogun and Johnson, 2004; Béliveau, 2013; Béliveau and Champagne, 2016; Burnes and Jackson, 2011; Freeman and Auster, 2011; Gagliardi, 1986; Hannah et al., 2013; Hernandez et al., 2013; Kotter, 1995; Longenecker and Longenecker, 2014; Lukas et al., 2007; Melkonian, 2004; Raelin and Cataldo, 2011; Rosemond et al., 2012; Rouleau, 2005; Schaubroeck et al., 2012; Schein, 2010; Schimmel and Muntslag, 2009; Shortell et al., 2015; Simons, 1999; Smith, 2003; Soparnot, 2011).

External Factors

The framework also represents elements outside of the control of the organization that nonetheless carry the potential to significantly influence implementation and outcomes. These include factors related to health care's business, policy, and payer environment that can create powerful incentives for adopting PFEC approaches. Examples include

- Reimbursement structures that reward organizations for adoption of key PFEC principles or for high performance on patient-reported measures of quality [4].
- State legislation that mandates support for family caregivers to be prepared to support their loved one's transition from the hospital [5].
- A shift toward greater transparency around health care outcomes to support patients and families in making more informed decisions about their care and treatment [6, 7, 8].

BOX 2
Examples of Health Care Organizational Assessment Tools

Agency for Healthcare Research and Quality (AHRQ) Working with Patients & Families as Advisors Implementation Handbook

Resource to facilitate patient and family partnerships with health care systems in implementing quality and safety efforts [9].

Gordon and Betty Moore Foundation and HRET Patient and Family Engagement Survey

A survey developed and fielded by the American Hospital Association's Health Research and Educational Trust (HRET) to assess hospitals' use of patient and family engagement strategies [10].

Healthcare Transformation Task Force's Addressing Consumer Priorities in Value-Based Care Guiding Principles and Key Questions

A collection of operational questions to guide health care organizations in fostering partnership, setting benchmarks, and evaluating progress toward transformation to value-based, person-centered care [11].

Institute for Patient- and Family-Centered Care Organizational Self-Assessment

Brief organizational assessment tool that can be used to identify organizational priorities for patient- and family-centered care and to facilitate measurement of progress [12].

Partnership for Patients (PfP) Strategic Vision Roadmap for Person and Family Engagement

Provides a "Strategic Vision Roadmap" to align patient and family engagement strategies [13].

Person-Centered Designation Self-Assessment

An evaluative framework of the organizational systems and processes necessary to sustain organizational culture change that guides organizations toward superior levels of practice of person-centered care [14].

PFCCpartners' Workplan

Guides organizations to create annual goals for integrating engaged care practices [15].

Organizations recognized as early trailblazers in PFEC encouraged and supported patients' and families' participation in care delivery and improvement because of a philosophical conviction that it was the right thing to do. The experiences of these organizations demonstrate that those intrinsic drivers can, in some cases, create sustainable change. However, for many organizations struggling to balance a host of competing demands, these intrinsic motivators are not enough to maintain PFEC as a strategic priority. External factors—particularly those with a direct impact on financial results—minimize the risk of PFEC efforts losing steam, because losing steam translates into losing money. Consequently, these external levers, including reimbursement models, accreditation standards, legislation, public reporting, and more, must be in place to set the stage for PFEC to become an expectation for how care will be delivered and how health systems will operate.

This is not to suggest that organizations should delay progress on activities depicted in the framework until external levers are in alignment with PFEC. The framework acknowledges external levers as powerful incentives that can affect the pace of change. Thus, cultural change must target needed adjustments in these contextual factors; however, their absence or varying level of existence between and among health systems need not halt progress. Indeed, lessons learned from organizations currently implementing PFEC strategies can be used to foster changes in external levers.

Strategic Inputs

Having established the conditions that create a strong foundation for a culture of PFEC to emerge, the next section of the framework guides the user to specific interventions and tactics for creating the desired outcomes. These elements are organized into four types or categories: structures; skill and awareness building; connections; and practices.

Structures

The structures depicted in the framework refer to organizational systems and norms—in other words, how an organization operates. (This differs from individual behaviors and actions, which is captured in the “Practices” section.) The building blocks for a culture of PFEC are the organizational and physical structures that break down the barriers, both literal and figurative, between care teams and patients and families. Erected over generations, these barriers have perpetuated and preserved a hierarchical system of care. Intentionally or not, these health care norms have shielded patients from their own health information, have encouraged care partners to keep their distance in order to let the professionals do their jobs, and have organized much of how care is delivered around the convenience of providers versus the preferences and priorities of patients and families. As antidotes to these customary barriers, the structures referenced in the framework work together to create avenues for patients’ and families’ active participation not only in care processes, but also in quality improvement efforts.

Structures promoting transparency, visibility, and inclusion among patients and families include organizational infrastructure that essentially brings patients and family members into the fold, formally enlisting them as partners in creating better health care experiences, systems, and outcomes. These structures proactively create channels to and from executives, governing bodies, care teams, and clinical researchers that generate the kind of collaboration and partnership that will ultimately foster true co-creation of a patient-centered health care system. Whatever form these structures take, in order to promote true inclusion, it is imperative that participation of individuals representative of the population served be prioritized. Examples of such structures include

- Members, chairs, or co-chairs of a Patient and Family Partnership Council;
- Members of rapid improvement teams testing change ideas;
- Full members of safety and quality improvement committees, facility design planning committees, and committees planning, implementing, and evaluating new policies, practices, and programs;

- Members of in-person or virtual groups creating, implementing, evaluating health information resources and education programs for patients and families;
- Patient and family educators for employee orientation, continuing education for senior leaders, front-line staff and clinicians, and education for students and trainees;
- Partners with researchers in designing, conducting, and disseminating studies that answer questions and evaluate outcomes that matter most to them,
- Members on root cause analysis teams (for very experienced, well-prepared patient and family advisors); and
- Appointed member(s) of the system’s governing body or bodies (for very experienced, well-prepared patient and family advisors).

Anecdotally, organizations with a culture of PFEC often find that, although initially integrating patients and family members into existing committees and organizational structures may feel awkward, the value these voices bring prevails over the uneasiness. This often-times paves the way to the realization that something is missing from many committees that have not taken the step to invite patient and family participation.

The governance structure of health care organizations has also created barriers among personnel. The structures represented in the framework dismantle many of the siloes so prevalent in health systems today. *Structures promoting transparency, visibility, and inclusion among personnel* include shared governance models, leadership rounds, town hall meetings, multidisciplinary improvement teams, and systems for keeping all staff aware of organizational performance against key strategic indicators.

Adapting personnel management practices to align with PFEC and creating staff appreciation/reward structures that reinforce those values sets the expectation that regardless of an individual’s role in an organization—clinical or nonclinical, director or frontline staff—all health care professionals share in the responsibility for patient and family engagement. This may take the form of behavioral expectations or core values that establish explicit expectations for how personnel interact with patients, families, and each other. It could also include the adoption of shared goals and/or individual performance goals that relate to PFEC. See Box 3.

BOX 3

Example from the Field: Hiring for Fit at Stamford Hospital

When Stamford Hospital in Stamford, Connecticut, needed to hire staff for its environmental services department in a new hospital, the team sought to take advantage of each touchpoint during the recruitment and hiring process to model its organizational culture of patient-centered care. Tools were developed to identify candidates who possessed characteristics that had been deemed the most important attributes for the position: high energy, friendliness, a can-do attitude, team-player orientation, and flexibility. Importantly, this list of desired attributes was largely informed by current staff within the department. Phone screenings narrowed down the field of candidates who were invited to a recruitment event where those desired team member attributes were on full display. Environmental services staff participated in the event, sharing insights about the culture of the department and emphasizing the patient as the core of their role in housekeeping. Housekeeping staff also joined candidates' interviews, which were structured in an "American Idol" panel style, with a focus on customer service and communication. Panelists were encouraged to share personal examples of teamwork and compassion in action. All of these activities were designed to select the candidates who would best fit within the hospital's unique patient-centered culture.

Promoting *interdisciplinary* as well as *cross-sector collaborations* advances teamwork that, in turn, promotes improved care, health, and experiences for patients and families. In a culture of PFEC, health care professionals and other staff work across departments, sectors, disciplines, and care settings to personalize care around patients' and families' expressed goals and priorities and to create more coordinated and effective transitions between care episodes.

In the most literal interpretation of "structures," the framework calls out the importance of a *built environment that facilitates PFEC*. These environmental features focus less on the surface-level aesthetics of a space and more so on how the design of the physical space can facilitate improved communication and education, increased family involvement, and partnership between patients and care teams. Examples include

- Designing patient rooms with ample space, seating, and overnight accommodations to encourage a family's presence;
- Organizing consultation spaces to "level the playing field" between doctors and patients by replacing traditional big desks that create distance with couches, small tables, or arm chairs that promote connection; and
- Adopting decentralized, open nursing stations that increase the visibility and accessibility of personnel.

Today, patients' and family members' engagement with the health care system is hardly limited to in-person interactions. Accordingly, these structures

must also include technological infrastructures that support patient and family engagement. This area is rich with opportunity given our reliance on technology to guide interactions, share information, and promote quality and safety. Consider that electronic medical records rarely have fields to capture patients' most pressing needs and priorities *as they themselves have identified them*. The failure to create systems that capture this information perpetuates the notion that this patient information is discretionary versus essential. At the same time, it impedes the ability of care team members to share these important details with each other. Patient portals, which have demonstrated progress inviting patients and families to be informed about their care in near real time, still mostly limit access only to that which is fed into the portal, and most have a long way to go toward providing individuals and their care partners meaningful opportunities to contribute to the portal or codesign their care. *See Box 4.*

Skill and Awareness Building

PFEC represents a significant shift in how health care professionals and other staff interact with patients and families, and vice versa. Prevalent features of the health care experience have long included restrictive visiting hours in hospitals, treating the medical record like a classified document, and essentially all care planning completed by clinicians with limited consideration of patients' preferences and values. In this historic, more provider-centric model of care, patients' deference and compliance has been viewed as positive traits that would bode them well in their health care. In

BOX 4

Example from the Field: Open Notes

Open Notes is a national effort designed to remove the customary barriers that have restricted patients' access to their doctors' visit notes. In 2010 more than 100 primary care physicians in three settings participated in a 12-month study, during which time they shared their visit notes online with patients. The study findings suggest that adopting this level of transparency and creating greater access for patients to their doctors' notes about them has the potential to make care more efficient, improve communication, and drive greater patient engagement in their own health and health care (Delbanco et al., 2012).

a culture of PFEC, however, individuals and their care partners are urged to take a much more active and participatory role.

Correspondingly, many health care professionals have become accustomed to fairly rigid rules and guidelines with the goal of standardizing care (with varying degrees of success). In a culture of PFEC, these same staff are invited to personalize care to accommodate the expressed preferences of those for whom they are caring. Furthermore, studies have long been designed to examine outcomes identified by scientists as important. In a culture of PFEC, studies are designed with patients and family caregivers to examine aspects and outcomes of care that matter most to them. Finally, executives have long relied on the insights and recommendations of their clinical champions, financial officers, and governing body to create strategic and operational plans. In a culture of PFEC, executives expand these perspectives with the voices of patient and family partners. While patients and families may have a steep learning curve when it comes to health care operations, their personal experiences and insights are invaluable for creating systems that will work best for them.

These changes in behaviors and attitudes cannot simply be willed into existence. We must provide *training for health care personnel* to help them build the skills necessary to interact in ways that facilitate shared decision making, family involvement, and the delivery of care with compassion and empathy. Associated training and development activities include all clinical education and training, increased multidisciplinary and team-based education and training, as well as ongoing continuing medical education, training, and skill development. Involving patients and families as faculty in the training activities outlined above reflects

a new level of respect and commitment to inclusion. Supporting this degree of engagement requires skills and competencies that may fall well outside of the comfort zone of many leaders, which highlights the need for skill-building opportunities for leadership as well.

Engagement is a two-way street. To train health care professionals to support greater engagement is in vain if there are no corollary *skill-building opportunities to expand patient and family caregiver capabilities to be full partners in care and quality improvement*. Patients, families, and health care personnel need to develop the skill sets that enable true collaboration. Intentionally or not, the dynamics in health care delivery have been created by years of provider-centric systems that have subtly (and not-so-subtly) cast patients as subjects and spectators of their own care. These messages have dictated norms about patients' attitudes and behaviors that first have to be unlearned before new skills can be taught to supplant those old habits. A warm message in a new patient welcome packet asserting the importance of patients being involved in their care will not change these behaviors. What is needed is alignment between what patients read about what they can expect from their care and how that care is actually delivered. They need to see their engagement proactively prompted by their care team ("Let me be sure I've done my job and explained everything clearly. Could you share in your own words your understanding of what I just said?"). They need engagement to be modeled, and they need their care team to meet them where they are, acknowledging that there is an engagement continuum and there must be on-ramps and entry points at various engagement levels. Not every individual will be ready to independently complete a decision aid and come to a health care appointment prepared for a shared

decision-making conversation. But those same patients may be very receptive to a medical assistant asking them to share the top concern they want to be sure is covered during their visit that day to guard against leaving with all the doctor's chief concerns covered, but none of their own addressed.

Importantly, patients and their care partners must be *invited* to engage in a reciprocal relationship and to help define what engagement looks like and why it is important if we are to achieve success in advancing PFEC. In addition, patients and families must be familiarized with tools and techniques that will “activate” them and will increase their health confidence. *See Box 5.*

Finally, recognizing that knowledge drives change, greater effort must be made to ensure that research findings are communicated in a way that makes sense to those at the front lines of health care. The *development, sharing, and translation of research for health care personnel and patients and families* creates greater access to the most current knowledge about treatment options and methods to those who, ultimately, the research was done to benefit.

Connections

The activities portrayed in this section of the guiding framework build connections in two ways. First, they weave together the PFEC skill-building elements designed for health care personnel with those designed for patients and family caregivers. This *connection of skill building for personnel and patients and families* to work as a team creates common expectations, language, and tools for what it means to work collaboratively and what it requires from all involved parties.

The other aspect of connection building included is supporting health care professionals to engage at a personal level to the concepts and values of PFEC. *Experiential learning* to promote perspective taking and connection to purpose helps personnel to understand and internalize how their attitudes, behaviors, and actions—regardless of their role in the organization—are connected to a greater sense of purpose. One effective approach to build connection is to invite patients and families to share their stories with the organization. A patient who shares a story of their experience with the specific organization has a more profound impact than a story that feels more distant or detached—and perhaps less pertinent—to the organization. Care

BOX 5

Examples of Tools to Enhance Engagement of Patients and Families

Ask Me 3®: A set of three questions developed by the National Patient Safety Foundation to prompt patients to be more active members of their health care teams [16].

The Batz Guide for Bedside Advocacy: Available as a free download and as an iPad app (in versions for adults and children), this tool developed by the Louise H. Batz Patient Safety Foundation helps patients and families partner more effectively with their care team to promote patient safety [17].

CFAH Engagement Behavior Framework: Developed by the Center for Advancing Health (CFAH), this tool provides a comprehensive list of behaviors and actions both patients and caregivers may take to optimize their health care [18].

I Wish I Had Asked That!: A tool developed by the Informed Medical Decisions Foundation to help guide patients to have more constructive and satisfying conversations with their care team [19].

Patient Preferences Passport: A user-friendly, patient-owned tool that consolidates important patient information ranging from medical diagnoses and prescriptions to patient-report details such as personal health goals, care preferences, their most pressing concerns, and what supports they rely on to manage their health—all captured in the patient's own voice. The questions included in the passport derive from patients and family members themselves, drawing on personal experiences of what they felt was important for their caregivers to know when planning their care [20].

Your 1, 3, 6, 12 Month Plan to Becoming an Empowered Patient: Developed by the Empowered Patient Coalition, this tool offers a series of staged steps patients can take to become more engaged and active participants in their own health care [21].

team members can also be supported in better understanding the perspective of patients through exercises designed to have them “walk in their patient’s shoes.” See Box 6.

Another example is patient-centered retreats, a hallmark of the Planetree culture change approach that combines skills development with inspiration and team building to support health care professionals in connecting to their deeper motivations for being a professional caregiver (Guastello and Frampton, 2014). Individual and organizational testimonies routinely credit these connection- and perspective-building activities as a cornerstone for creating and fortifying a culture of PFEC. Leadership rounds, where health system executives, clinical, and administration leaders routinely round on patients on units to discuss their experiences receiving care also facilitate PFEC. Indeed, without intentional efforts to create this connection to purpose, all the other PFEC inputs building out the framework run the risk of being perceived as “just one more thing to do.”

Practices

The practices depicted in the framework are methods, processes, and behaviors adopted by teams to guide health care interactions. Whereas the structures address how the organization operates, the practices guide how individuals within the organization behave and interact with each other. These practices bring the concept of PFEC to the bedside, to the exam room,

to the consultation space, and out into the community forming how patients, families, and health care professionals experience PFEC in their interpersonal interactions. *Practices that promote patient and family engagement* like bedside shift report, shared medical records, shared decision making, teach back, care partner programs, collaborative goal setting, and patient pathways, among others (see Box 7), ensure that engagement opportunities are leveraged at key patient touchpoints—before, during, and after a care episode. They work cooperatively and cumulatively to build trust, build reciprocal relationships, open lines of communication, redefine what is considered “vital” patient information, and create more effective partnerships among patients, families, and their care teams. The adoption of structured approaches for executing these practices, such as tools, guidelines, and other implementation supports, reduces variability in how PFEC is delivered provider to provider, shift to shift, and day to day.

Introduction of any of these practices should draw on the structural inputs depicted in the framework to promote co-creation in the implementation. Involving the frontline staff who will be carrying out the practices facilitates a smoother integration into work flow and enhances the likelihood of sustainability after the initial luster of a new practice has worn off. It is also vital to involve patients and families in the design and evaluation of these new practices to ensure they meet their needs in a meaningful way. Without this

BOX 6

Example from the Field: Northern Westchester Hospital’s Management Overnight Program—Through the Eyes of the Patient

In 2014, Northern Westchester Hospital in Mount Kisco, New York, began requiring each manager (clinical and non-clinical) to spend at least one night in the hospital in the role of a patient. Managers are randomly paired in teams (a clinical manager with a nonclinical manager) and each team is assigned a specific month in which to complete the overnight. Members of the hospital’s Patient Partnership Council were instrumental in the development of the initiative, providing input into the design, such as recommending that teams wear gowns during the experience and have their sleep interrupted for tasks like vital signs to be completed. Other aspects of the experience include being transported by stretcher or wheelchair, sleeping in hospital beds or care partner pullout couches, shadowing patients and staff, eating patient meals, making observations, and documenting their findings using structured feedback tools.

Since the program’s inception, 75 managers have participated and provided feedback, which is tracked and trended for performance improvement purposes. A quarterly report-out of key findings is shared with the leadership team and the Patient Partnership Council. Beyond the specific recommendations made, another important outcome of this work has been managers expressing how the experience has altered the way they perceive the patient experience with enhanced mindfulness and understanding of what it is really like to be a patient at the hospital.

involvement, implementation of these practices could devolve into little more than a checklist of practices that sound good but make little difference in the experiences of patients and families.

Organizations with a culture of PFEC recognize that health is more than just physical, and a healthy organization is concerned not only with the well-being of its patients but also the well-being of families and health care professionals. As such, these organizations implement *practices tending to the emotional, social, and spiritual needs of patients, families, and personnel*. These practices promote a holistic state of health and wellness, recognizing that treating physical needs while neglecting emotional ones falls short of quality care. This includes adoption of practices for conveying compassion, building on a growing body of evidence demonstrating that compassionate care creates better health care outcomes (Haslam, 2007; Hojat et al., 2011; Rakel et al., 2011). Another example is the use of a spiritual assessment or a history tool to guide care planning that takes into account a person's

spiritual beliefs and preferences. As indicated in the model, these practices also extend to health care professionals. They aim to preserve staff's well-being and their ability to provide high-quality, compassionate care. Examples include staff services to help support work—life balance, space and time to decompress and debrief from emotionally draining interactions, and support around issues of grief.

Practice Outputs

The outputs depicted in the framework are the direct results of implementing the inputs. They are shorter-term results and may be used as measures to gain a more immediate understanding of the impact of the various tactics and approaches. The wide range of intermediate benefits reflects that there are many different ways to examine the impact of PFEC, including clinical indicators like infection rates; operational indicators like utilization, malpractice claims, number of grievances, and length of stay; patient-reported indicators like health confidence, feelings of autonomy,

BOX 7 Examples of Practices that Promote Patient and Family Engagement

Bedside Shift Report: A patient-centered adaptation of the traditional nursing task of shift report to include the patient (and family caregivers as appropriate) as active participants and contributors in the exchange of essential patient information between care team members (Planetree, 2014a; Radtke, 2013; Reinbeck and Fitzsimons, 2013).

Care Partner Program: A program that formalizes the involvement of those who comprise a patient's social support network (and those will continue to support the patient in managing their care after discharge) as a member of the care team who is involved in providing hands-on care where appropriate, as well as care planning (Frampton et al., 2010; Planetree, 2014b).

Collaborative Goal Setting: A process wherein the patient and care team jointly arrive at mutually agreed-upon areas for treatment or change that address patient preferences and priorities, as well as the care team's clinical concerns (Schaefer et al., 2009).

Patient Pathways: A tool modeled after traditional clinical pathways, which aim to standardize health care practice for a particular condition, but is written explicitly for patients and family caregivers in plain language to describe the typical care and treatment of patients with a specific diagnosis (Frampton et al., 2008).

Shared Medical Records/OpenNotes: Refers to the patients' ability to access their real-time, in-progress personal health information during a care episode, for example, during a hospitalization and/or treatment (Delbanco et al., 2012; Planetree, 2014c).

Shared Decision Making: The process of interacting with patients who wish to be involved in arriving at an informed, values-based choice among two or more medically reasonable alternatives (Elwyn et al., 2012; O'Connor et al., 2014).

Teach Back: A technique for validating patients' comprehension of vital information conveyed to them by a member of the care team by asking the patient to restate in his or her own words what they heard (Brega et al., 2015; DeWalt et al., 2011).

and decision quality; and patient-prioritized indicators like sleep quality, family presence, effective communication skills, and the quality of the relationship with their care team.

Monitoring, Data Collection, and Continuous Feedback Increasing Levels of Co-Creation

This section of the framework is intended to demonstrate what it takes to create a continuous learning organization where implementation activities are guided by an ongoing process of discovering needs and opportunities, applying new knowledge, and assessing and adapting to implement structures, practices, skill- and connection-building activities that build on and draw from each other to create a culture of PFEC. This circular loop suggests that the whole of the foundations and inputs is much greater than the sum of the parts. Consider the example of developing skills among health care professionals to take a person-centered approach to preparing patients and families for the transition from hospital to home, including actively extending an invitation to patients and families to engage. However, the engagement grinds to a halt when the nurse realizes that organizational policy prohibits her from printing a medication list to share with the patient and family. These engagement gaps can only be identified and rectified through the *ongoing monitoring, data collection, and continuous feedback* illustrated in this portion of the framework.

The circular loop also suggests that a key component of this continuous learning is increasingly more participatory involvement on the parts of patients and family care partners. The model illustrates that a requirement for moving from the intermediate benefits to the outcomes is this increasing degree of coproduction or co-creation of health care, “in which patients and professionals interact as participants within a healthcare system in society” (Batalden et al., 2016).

Finally, this section of the framework conveys how knowledge informs continuous learning and improvement and guards against the rise of a “checkbox” mentality around PFEC. The field continues to evolve, and the publication of any set of standards, metrics, or guiding framework must be viewed as an encapsulation of the best evidence available at the time it was created, but never a final, definitive, all-encompassing accounting of PFEC elements. *See Box 8.*

The Evidence Base

The creation of a bibliography of the preliminary, foundational evidence base (*see Appendix B*) further enhances the usefulness of the PFEC framework by clearly delineating those elements that have been linked via research with better culture, better health, better care, and lower costs. Compilation of the bibliography was a collaborative process. During the final 4 months of the SAP's work, its scientific advisors shared their relevant research and associated it with elements of

BOX 8

Examples of Tools for Patient and Family Engagement in Health Care Delivery

CUSP Toolkit: Patient and Family Engagement

A module of the Comprehensive Unit-based Safety Program (CUSP) Toolkit developed by AHRQ, it provides information and resources for involving patients and family advisors as part of a safety team at the hospital unit level [22].

Guide to Patient and Family Engagement in Hospital Quality and Safety

Developed by AHRQ, it serves as an evidence-based resource for involving patients and families in safety and quality initiatives at the hospital level [23].

IHI Open School

An initiative of the Institute for Healthcare Improvement (IHI), it includes more than 30 online courses related to quality, safety, and patient-centered care, among other topics [24].

A Roadmap for Patient and Family Engagement in Healthcare Practice and Research

Funded by the Gordon and Betty Moore Foundation and developed by the American Institutes for Research, the Roadmap provides a guide to advance patient and family engagement across the health care continuum and includes resources for care and system redesign, among others [25].

the guiding framework. This evidence was organized into a database, where it was then filtered based on the associated element(s) of the framework, outcomes reported, and keywords.

Time and resource constraints did not allow for a comprehensive systematic literature review of each element of the logic model. So, while the bibliography is comprehensive in the sense that it includes all the citations put forth by SAP members, it is not exhaustive, nor should it be considered to be the defining evidence base for PFEC. Despite these limitations, however, a scan of the research incorporated into the bibliography helps to illuminate where the empirical evidence base and experience base are most closely aligned in support of the elements of the framework, and where there are disconnects that could help to guide a future research agenda for PFEC.

Areas Well Supported by Evidence

A number of the foundational elements identified in the framework are well supported by a rich collection of studies on organizational culture and change management principles. Many of these are fairly broad in nature; however, they are supplemented with the work of a smaller group of researchers who have examined person-centered change management (Béliveau, 2015; Béliveau and Champagne, 2016). The ability to draw on these researchers' work to explore the nuances of how organizational culture and change management principles apply within the dynamics of health care organizations striving toward patient-centeredness adds greater credence to the inclusion of items, including the need for PFEC to be identified as a strategic priority; change champions to promote PFEC; and industry, business, policy, and payer incentives to align with PFEC as key foundational elements.

Within the strategic inputs section, there is a well-established research base for environmental features in support of PFEC. This evidence supports the need for a physical environment that increases family presence (Choi and Bosch, 2012), improves communication (Ajiboye et al., 2015; Rippin et al., 2015), improves sleep and relaxation (Bartick et al., 2009; Bauer et al., 2015), and may help reduce infection (Biddiss et al., 2013). *See Box 9.* Krumholz's work (2013), however, demonstrates that the creation of a healing environment requires more

than environmental *enhancements*; it also requires the reengineering of care patterns and systems that have been part of business as usual for years in health care, but that may potentially be compromising the well-being of patients precisely at times when we are trying to get them well. This work posits that by proactively addressing common environmental stimuli (like alarms, light exposure, etc.) and psychological stimuli (like forced fasting, pain, anxiety, and uncertainty), hospitalized patients' physical and mental well-being will be better, which will result in a positive impact on their symptoms, function, and quality of life.

A number of studies were identified in support of the practices section of the framework. In particular, organizations embarking on the implementation of practices to facilitate shared decision making (Arterburn et al., 2012; Barry et al., 2008; Bozic et al., 2013; Elwyn et al., 2012; Ibrahim et al., 2013; Stacey et al., 2014; Tai-Seale et al., 2016; Veroff et al., 2013), family presence and involvement (Coleman et al., 2006, 2015; Luttik et al., 2005; Meyers et al., 2000; Rosland and Piette, 2010; Rosland et al., 2011), advance care planning (El-Jawahri et al., 2010; Volandes et al., 2013), and compassion in action (Del Canale et al., 2012; Hojat et al., 2011; McClelland et al., 2016; McClelland and Vogus, 2014; Rakel et al., 2011) can do so supported by research suggesting the potential of these strategies to drive improvements in outcomes. Pairing these scientific studies with practical implementation resources will be an important strategy for responding to two common sources of delay when it comes to PFEC implementation: the dual questions of *Why do it?* and *How to do it?*

Finally, the evidence in support of *training to expand partnership capabilities of health care personnel* suggests this as an important area of emphasis when building a culture of PFEC. Training in empathy, communication, and patient education emerged with a strong basis in empirical evidence (Atwood et al., 2016; Phillips et al., 2014; Riess et al., 2012; Tai-Seale et al., 2016; Wexler et al., 2015).

Research Gaps That Emerged

The corollary area of emphasis—*training to expand partnership capabilities of patients and families*—is not as well supported. Logically, philosophically, and conceptually it seems apparent that we cannot rely on

BOX 9

Example from the Field: The Somerville Protocol for Preserving Patients' Sleep

One study is setting out to prove that poor sleep need not be a forgone conclusion for patients. By establishing an 8-hour “quiet time” that includes staff-monitored noise and efforts to time vital signs and routine medication administration to minimize the need to wake patients up, one Cambridge Health Alliance hospital was able to reduce sedative use by 49% and reduce the top patient-reported source of disturbance keeping them awake—disruptions by staff—by 38% (Bartick et al., 2009).

patients and families to inherently have the capacity to actively participate in their care in a system that was designed without them, and that they need support to build that skill set. However, evidence is lacking to back up this common sense assertion. Furthermore, despite the evidence supporting clinical training in effective communication strategies to engage people to participate in decisions about their care, gaps persist around how to effectively engage patients and families to inform care delivery and design.

This research gap naturally extends into the *connection-building* activities in the framework, with only a few studies identified in this preliminary review to demonstrate the impact of such efforts to bridge the divide between how health care professionals are prepared to interact with patients and family caregivers in a way that supports their involvement and how the latter are prepared to engage.

The limited evidence included in this review around patient- and family-focused inputs designed to continuously and increasingly involve them throughout the health care enterprise (both at the point of care and in system-level improvement) is also reflected in the infrastructural inputs. A disparity appears between the levels of investigation, to date, around the impact of structures that promote transparency, visibility, inclusion, and continuous learning among health care professionals and the companion-type structures that promote a comparable degree of openness and participation among patients and family caregivers. Though anecdotal testimonials to the power of such partnerships are becoming more prevalent, this area of inquiry would benefit from large-scale studies of patient engagement in quality improvement efforts. A particular area that emerged for more rigorous exploration is the continuous learning depicted at the center of the guiding framework and the relationship

between outcomes and the degree of advancement of co-creation with patients and families.

Another area where the empirical evidence base does not seem to have caught up with the “experience base” is in the *connection-to-purpose* inputs. The feedback from sites offering experiential activities that create a shared sense of purpose among health care professionals is believed to be critical for anchoring the culture change effort around a common understanding of what matters most. In focus groups and programmatic evaluations, participants of Planetree retreats have attested to the experience being one that truly helped to personalize, humanize, and demystify the concept of patient-centered care and enabled them to understand their role in advancing the values of PFEC. However, there appears to be an opportunity to more scientifically examine the extent to which these experiential learning opportunities create sustained changes in individual team members' behavior and whether these experiences directly correlate to the Quadruple Aim outcomes.

Finally, attempts to evaluate the relative impact of patient and family caregiver involvement in research remains in the early stages. Such involvement is depicted as an important element of the organizational structures, skill building, and practices portrayed in the framework. Greater research is needed, however, on the best methods for engaging patients in health care research (Domecq et al., 2014; Esmail et al., 2015; Fagan et al., 2016).

A Note on Outcomes

As it relates to outcomes, the evidence scan completed in support of the framework was, overall, very encouraging. The bibliography referencing the existing and emerging research reflects increasing interest and progress in solidifying the case for adopting

a culture of PFEC as a means of driving better culture via the engagement of patients, family caregivers, and the workforce; better health; delivering better care experiences; and creating greater value—and, notably, recognizing all of these outcomes as equally important. In particular, the framework and associated evidence base indicate that the patient experience in and of itself is a legitimate outcome and not merely a driver of population health and lower costs. As evidenced by the rapidly growing field of patient-reported outcomes, a more comprehensive and inclusive definition of exactly what a “desired treatment outcome” means is needed. Movement from largely clinically defined quantitative measures alone to patient-reported quality of life and functional measures also needs to be accelerated.

However, vital to building the momentum needed to make PFEC the norm in health care is ensuring that the evidence base addresses the areas of greater interest and concern of patients and families as well as health system executives. In both cases, the evidence is lacking. From the patient and family point of view, there is a need for more research examining the impact of PFEC on outcomes that matter most to them. Such patient-prioritized outcomes include improved quality of life, match between care plan goals and patients’ expressed goals, and functional status—and yielding those outcomes at lower out-of-pocket costs. When it comes to developing, evaluating, and applying these patient-reported outcome measures, however, there is considerable opportunity to more actively encourage approaches that bring together researchers and patients to better understand the discrepancies between patients’ and clinicians’ perspectives of what outcomes are most important (Staniszewska et al., 2012). *See Box 10.* For health system executives, the business case for PFEC depends on stronger evidence of the impact of essential PFEC elements on operational outcomes, including improving efficiency and reducing waste and total health care costs.

Next Steps and Future Opportunities

Informed by both the scientific evidence base *and* the practical experience base, the guiding framework presented here serves as an accelerator to achieve a culture of PFEC by setting out a pathway for organizations to apply in leveraging PFEC as a driver for better

culture, better health, better care, and greater value. In order to support this vision and continue moving forward, we propose a series of activities that draw on the framework as a culture change tool.

Promoting Greater Inclusion and Accessibility

We begin with an expansion of review and opportunities for more patients, family members, and patient engagement advocates to vet and refine the framework. We must ensure that the tool, and the formats and language used to describe it, meets the needs of these groups. We must engage patients and family partners in co-creating future iterations of the framework in order to ensure maximum accessibility and understanding among patient and family leaders.

Similarly, engaging other health care stakeholders, such as system executives, clinicians, researchers, purchasers, payers, policy makers, industry, and medical education and training institutions, in reviewing and contributing to the PFEC framework, suggesting the language and evidence that is most useful to clinicians and decision makers, is key.

Perhaps one of the most significant challenges is to ensure the inclusion and proactive engagement of underserved, “hard-to-reach,” and “complex” patients and their caregivers. Some examples of medically complex patients are patients with multiple chronic conditions, high utilizers of care, and patients with major social risks, cognitive impairment, and behavioral health issues, to name a few. It is essential that all PFEC efforts include the perspectives and involvement of these groups.

Expanding the Evidence Base

The bibliography compiled in support of the framework represents a preliminary collection of relevant studies for a broadened definition of PFEC—but it is not the complete, defining evidence base. There is tremendous opportunity to contribute to the field by conducting a systematic literature review of the broader impact of PFEC on the Quadruple Aim as well as on each element in the framework. This review should incorporate information on underserved and hard-to-reach populations across all aspects of the model. Given that PFEC remains an actively evolving area of inquiry, the creation of an organic database, structured by the elements of the framework and enabling

BOX 10

Patient and Family Engagement in the Research Enterprise

The vision of a continuously learning health system is that all health care delivery settings routinely capture, assess, and translate information to improve culture, processes, and interventions that will result in safer, better quality care, as well as outcomes that matter most to patients.

While not all health systems perform clinical research, it is critical to note the importance of this enterprise in advancing PFEC. Similar to the health care delivery landscape, in recent years significant effort and resources have been invested in the vision of advancing a more patient- and family-centered and engaged research enterprise. This work has led to the coining of a new type of research called “patient-centered outcomes research” (PCOR). PCOR incorporates the experiential knowledge of patients, families, and other relevant stakeholders as partners in the design, conduct, and dissemination of research, ensuring that the findings of the research—and outcomes studied—are more patient centered, relevant, and useful to better inform patients and clinicians about treatment options.

Engaging patients and other stakeholders as equitable partners in research is increasingly recognized as a promising approach to yield actionable evidence for clinical decision making and improved outcomes. As a result, numerous frameworks, tools, and resources have been developed to support patient and family (and broader stakeholder engagement) in research. Some examples include the following.

HIPxChange: An assortment of toolkits developed at the University of Wisconsin for engaging patients and families in research and health system change [26].

A Pragmatic Framework for Authentic Patient-Researcher Partnerships in Clinical Research: A framework for collaborative engagement and partnership between research investigators and patient/family advisors from existing patient and family advisory council. The framework breaks down the roles for each party throughout the clinical research process (Fagan et al., 2016).

PCORI Engagement Rubric: Provides guidance to research teams applying for Patient-Centered Outcomes Research Institute (PCORI) funding to involve patients and other stakeholders in all phases of the research process [27].

University of Maryland PATIENTS Program: Promotes multistakeholder partnerships and engagement in research, conducts research, and produces and shares education and training on engaged research [28].

Value+ Toolkit: Produced by the European Patients Forum, provides a comprehensive overview and resources for involving patients and families in research [29].

individuals to continually add evidence as it is generated, would provide an important resource to the field.

Reconsidering Criteria for Evidence Quality

The additional evidence analysis outlined above also should include an evaluation of the strength of the evidence base, noting which elements of the framework are supported by research that may rank low in quality in current evaluation models. This type of evaluation may highlight if and how current research evaluation models are biased against methods that help us further understand the needs and preferences of patients and families and, potentially, provide insights to evolve research ranking models.

Current models of assessing the strength and quality of scientific evidence continue largely in accor-

dance with the traditional biomedical model. These existing rubrics are based on a hierarchy that reserves the highest-quality rating for randomized controlled trials and meta-analyses and generally grades evidence from more observational, qualitative, or case studies as low quality. Consequently, members of the SAP expressed reservations that the types of evidence that would feature greater patient and family involvement (a fundamental principle for research around PFEC as depicted in the framework) would fall within the realm of the lower-quality evidence, despite the fact that this involvement of patients and families is considered essential for ensuring the research is aligned with patient and family priorities.

With this in mind, the SAP suggests the exploration of additional criteria for evidence review that

embraces a broader definition of what constitutes evidence quality. For example, such a system might enable traditional assessments of research quality to assign high marks for mixed-methods research. In this way, randomized controlled trial study design and methods will continue to score well, while also providing high marks for those rigorous studies that include a qualitative dimension.

Promoting Greater Alignment

Early efforts on the part of some key health care industry and advocacy groups helped to move the PFEC paradigm shift forward. Many of these efforts have continued and have been formalized into certification and accreditation programs that promote, recognize, and/or reward PFEC. The degree to which there is both alignment and consistency of standards found in such programs serves to strengthen overall PFEC efforts. For example, requiring that shared decision making be included as a foundational strategy supporting PFEC can be found in the Joint Commission's hospital accreditation standards, the NCQA Patient Centered Medical Home standards, and the Planetree Patient-Centered Designation criteria, among others.

Federal demonstration and innovation programs have also included either requirements for patient engagement or precursors to active patient involvement, like staff training in effective communication skills. Many of these initiatives were included or created through the Patient Protections and Affordable Care Act (ACA), such as the Medicare Shared Savings Programs, accountable care organizations, and Meaningful Use. Others predated the ACA, including bundled payment plans and federally qualified health centers. Still others are emerging out of these efforts in the hope of furthering transformation to a more patient and family engaged health care system. Recent examples include federally funded state innovation model programs, the Comprehensive Primary Care Initiative, the Transforming Clinical Practice Initiatives, the End Stage Renal Disease (ESRD) Networks, Partnership for Patients, and Quality Improvement Organizations.

Collectively these efforts have used the levers of accreditation and financial incentives to align system improvements with PFEC. An additional quality and financially driven change agent has been the movement

toward value-based care and the inclusion of patient experience measures in Centers for Medicare & Medicaid Services (CMS) reimbursement calculations. Recognizing the importance of not only what care is provided to patients but also how effectively it is provided *from the patient perspective* has literally changed the conversation of health care leaders today. The evolution of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) suite of surveys, along with public reporting of results, has helped to align measure development with PFEC goals.

In each of these programs, there is a mandate for patient and family engagement, and yet many organizations charged with implementing these programs continue to struggle with the varying standards, measures, and demands, exactly where to start, what practices to implement, and how to sustain these efforts. We believe the value of this framework extends to both the organizations struggling by providing direction and clarity, and the entities developing these programs, standards, and mandates. Only by aligning standards, measures, and activities with evidence-based approaches will we be able to achieve true system transformation. The framework is a resource that can inform the continued evolution of these programs in a way that aligns with the most current knowledge and evidence around PFEC, and to promote alignment of efforts to drive system-wide transformation.

Exploring Measures of PFEC and Measure Gaps

In addition to value-based care measures, there are a number of other innovative measurement efforts under way that offer opportunities for the productive use of the PFEC framework as a basis for comparison of the consistency and alignment between various efforts. CMS's Partnership for Patients initiative, for example, established a set of five patient and family engagement metrics for hospitals, all of which align with the framework. The National Quality Forum's work on patient-centered measures and IOM's *Vital Signs: Core Metrics for Health and Health Care Progress* (IOM, 2015) both include person-centered and individual engagement metrics as well. There exists a significant opportunity to harmonize such measures and integrate them into a consistent PFEC framework. As in all elements of the framework, measurement activities should include engagement with—and

measurement of the experiences of—underserved and underrepresented populations.

Building a PFEC Research Agenda Around Evidence Gaps

As discussed above, a series of gaps in the evidence base for PFEC emerged from the work of the SAP. These gaps continue to hamper progress in many areas critical to continued progress in PFEC. An important contribution of this effort, therefore, is to identify these evidence shortfalls such that researchers and institutions supporting research may be more proactive in their support of studies that could narrow these knowledge gaps.

Conclusion

The widespread implementation of patient and family engaged care holds vast potential for system-wide transformation to provide care that meets the needs and preferences of patients and families—by providing care that was designed with patients and families. Developed iteratively by a multistakeholder SAP, the guiding framework incorporates both the evidence base and the experience base and embraces organizational and practice elements beyond “traditional” PFEC drivers, including the related, but often overlooked, dimensions of workplace culture, the physical environment, the quality of human interactions, communication approaches, and other PFEC levers that impact health care culture, quality, experience, and value. The guiding framework organizes the rapidly growing evidence and experience base on how to create and sustain a culture of PFEC and serves as a tool to accelerate effective strategies to advance PFEC, promote effective partnerships among health care executives and patient and family leaders, and to guide broader policy efforts that intend to promote PFEC. The framework establishes and supports the notion that only through sustained, evidence-based action and collaboration will we achieve the Quadruple Aim of better culture, better care, better health, and lower costs.

Notes

1. Sharp Memorial Hospital in San Diego, California.
2. New York-Presbyterian Hospital/Westchester Division in White Plains, New York.
3. HRHCare in New York.
4. Patient Protection and Affordable Care Act, 42 U.S.C. § 18001 (2010).
5. AARP. The CARE Act: Helping Family Caregivers from Hospital to Home. March 7, 2016. Available at <http://blog.aarp.org/2016/03/07/the-care-act-helping-family-caregivers-from-hospital-to-home/>.
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7. The Leapfrog Group. Hospital Safety Score. Available at <http://www.hospitalsafetyscore.org/>.
8. U.S. News & World Report. Hospitals Rankings and Ratings. Available at <http://health.usnews.com/best-hospitals>.
9. Available at <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html>.
10. Available at http://www.hret.org/quality/projects/resources/more_foundation_patient_family_engagement_survey.pdf.
11. Available at https://static1.squarespace.com/static/548b623fe4b0991231a05ff0/t/57ab68e98419c2acafa34a5e/1470851306250/HCTTF_Addressing+Consumer+Priorities+in+ValueBased+Care+White+Paper_FINALPDF++FOR+DISTRIBUTION.pdf.
12. Available at http://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/better-together-organizational-self-assessment_eng.pdf?sfvrsn=2.
13. Available at <http://www.hret-hen.org/topics/pfe/FINALPFESTratVisionRoadmap.pdf>.
14. Available at <http://planetree.org/designation-2/>.
15. Available at <https://wordpress.com/pages/pfc-partners.com>.
16. Available at http://c.ymcdn.com/sites/www.npsf.org/resource/resmgr/AskMe3/AskMe3_Engaging-Patients.pdf.
17. Available at <http://www.louisebatz.org/patients/the-batz-guide/>.
18. Available at <http://www.cfah.org/engagement/research/engagement-behavior-framework>.
19. Available at http://cdn-www.informedmedicaldecisions.org/imdfdocs/Patient_Visit_Guide.pdf.
20. Available at <http://planetree.org/wp-content/uploads/2015/08/Passport-to-PlanetreeRev2.pdf>

21. Available at <http://empoweredpatientcoalition.org/wp-content/uploads/2015/02/13612MonthPlan.pdf>.
22. Available at <http://www.ahrq.gov/professionals/education/curriculum-tools/cusptoolkit/modules/patfamilyengagement/index.html>.
23. Available at <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html>. Available at <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html>.
24. Available at <http://www.ihl.org/education/IHIOpenSchool/Courses/Pages/default.aspx>.
25. Available at www.patientfamilyengagement.org.
26. Available at <https://www.hipxchange.org>.
27. Available at <http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>.
28. Available at <http://patients.umaryland.edu/>.
29. Available at <http://www.eu-patient.eu/global-sets/projects/valueplus/value-toolkit.pdf>.

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Author Information

Susan B. Frampton, PhD, is President, Planetree. **Sara Guastello** is Director of Knowledge Management, Planetree. **Libby Hoy** is Founder and CEO, PFCCpartners. **Mary Naylor, PhD, FAAN, RN**, is Marian S. Ware Professor in Gerontology and Director of the NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing. **Sue Sheridan, MBA, MIM, DHL**, is Director, Patient Engagement, Patient-Centered Outcomes Research Institute. **Michelle Johnston-Fleece, MPH**, is Senior Program Officer, National Academy of Medicine.

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APPENDIX A: NAM Scientific Advisory Panel on the Evidence Base for Patient and Family Engaged Care

Jim Atty, FACHE, Chief Executive Officer, Waverly Health Center

Bruce J. Avolio, PhD, Mark Pigott Chair in Business Strategic Leadership; Executive Director, Center for Leadership & Strategic Thinking; Management Department, Foster School of Business, University of Washington

Michael Barry, MD, Chief Science Officer, Healthwise; Professor of Medicine, part-time, Harvard Medical School

Julie Béliveau, MBA, DBA, Professor of Management, Business School, Université de Sherbrooke

Sheila Bosch, PhD, LEED AP, EDAC, Assistant Professor, Department of Interior Design, University of Florida

Eric A. Coleman, MD, MPH, Head, Division of Healthcare Policy & Research, University of Colorado Denver

Susan Frampton, PhD, President, Planetree, (Chair)

Dominick Frosch, PhD, Chief Care Delivery Evaluation Officer, Senior Scientist, Palo Alto Medical Foundation Research Institute

Sara Guastello, Director of Knowledge Management, Planetree

Jill Harrison, PhD, Director of Research, Planetree

Judith Hibbard, DrPH, Research Professor, University of Oregon

Mohammadreza Hojat, PhD, Research Professor, Thomas Jefferson University

Libby Hoy, Founder, PFCCpartners

Harlan M. Krumholz, MD, SM, Harold H. Hines, Jr. Professor of Medicine, Yale University

Laura McClelland, PhD, Assistant Professor, Virginia Commonwealth University

Mary Naylor, PhD, FAAN, RN, Marian S. Ware Professor in Gerontology; Director of NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing

David P. Rakel, MD, Professor and Chair, Department of Family and Community Medicine, University of New Mexico

Helen Riess, MD, Associate Professor of Psychiatry, Harvard Medical School, Massachusetts General Hospital; Chief Scientist, Empathetics, Inc.

Ann-Marie Rosland, MD, MS, Assistant Professor, University of Michigan Medical School; Research Scientist, Veterans Affairs Center for Clinical Management Research

Joel Seligman, President and CEO, Northern Westchester Hospital

Sue Sheridan, MBA, MIM, DHL, Director, Patient Engagement, Patient-Centered Outcomes Research Institute

Jean-Yves Simard, Management and Research Consultant, Institut de Recherche en Santé Publique, Université de Montréal

Tim Smith, MPH, Senior Vice President and CEO, Sharp Memorial Hospital

Susan Stone, PhD, RN, NEA-BC, CEO, Sharp Coronado Hospital; Senior Vice President, Sharp Laboratory Services

Carol Wahl, RN, MSN, MBA, Vice President, Patient Care Services, CHI Health Good Samaritan

APPENDIX B: Patient and Family Engaged Care: A Guiding Framework—Bibliography of Associated Evidence

Guiding Framework Element	Supportive Citations
FOUNDATIONS – LEADERSHIP	
Commitment to change	5, 13, 14, 41, 47, 51, 62, 65, 66, 71, 86, 99, 103, 106, 107
Leadership vision and behaviors aligned with PFEC	5, 12, 14, 21, 38, 41, 47, 51, 62, 65, 66, 70, 96, 99, 100, 101, 104, 107
PFEC as a strategic priority	13, 14, 51, 65, 66, 86, 106
FOUNDATIONS – LEVERS FOR CHANGE	
Assessment of current state	14, 51, 62, 66, 86, 101
Change champions	6, 7, 14, 62, 65, 66, 78, 101, 106, 107
Industry, business, policy, and payer incentives for PFEC	14, 62, 66, 101
INPUTS – STRUCTURES	
Shared governance	14
Promoting transparency, visibility, and inclusion among personnel and patients/families	13, 14, 19, 49, 50, 53, 62, 65, 66, 74, 78, 93, 100, 101, 106, 107, 121, 123
Fostering dialogue between clinical researchers and patients/families	18, 31, 35-37, 61, 109
Interdisciplinary and cross-sector teams	49, 50, 54, 74, 93, 103, 121
Cross-continuum collaborations	54, 66
PFEC-aligned personnel management practices	13, 14, 19, 62, 66, 68, 69, 78, 101, 106, 116, 119
Built environment that facilitates PFEC	2, 10, 11, 13-16, 22, 58, 62-66, 77, 78, 84, 85, 102, 106, 117
INPUTS - SKILL AND AWARENESS	
Training to expand partnership capabilities of health care personnel and patients/families	1, 4, 8, 13, 14, 28, 30, 34, 40, 42, 55, 67, 75, 76, 80-83, 88, 90, 103, 114, 115, 124
Development, sharing, and translation of research	18, 31, 35-37, 61, 109
INPUTS – CONNECTIONS	
Connection of skill building for personnel and patients/families	1, 40, 114, 124
Experiential learning	1, 14, 40, 45, 101, 107, 114
INPUTS – PRACTICES	
Promoting PFEC	1-4, 9, 14, 15, 17, 22-25, 27, 28, 32-34, 39, 40, 44, 46, 48, 52, 56, 57, 60, 67, 72, 75, 87-92, 94, 95, 98, 108, 110, 112-114, 118, 120, 121, 122, 126-128
Tending to the emotional, social, and spiritual needs of patients/families and personnel	4, 8, 10, 11, 13, 15, 30, 42, 55, 63, 68, 69, 79, 80, 119, 125
Engaging patients/families in research activities	18, 27, 31, 35-37, 61, 109

Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care

Guiding Framework Element	Supportive Citations
OUTPUTS – BETTER ENGAGEMENT	
Patient/family activation	1, 2, 4, 16, 29, 34, 41, 42, 45, 54, 60, 86, 116, 130
Increased family presence	23, 69, 74, 77, 90-92, 97, 99, 115, 130
Increased feelings of autonomy	77
Reciprocal relationships	31, 61
OUTPUTS – BETTER DECISIONS	
Improved health confidence	17, 28, 112
Improved decision quality	17, 35, 110, 122, 126
OUTPUTS – BETTER PROCESSES	
Improved care coordination	4, 24, 25, 27, 28, 46
Culture of safety	107
OUTPUTS – BETTER EXPERIENCE	
Improved sleep	10, 11, 48
Reduced stress	35, 59, 74
Improved communication	1, 2, 17, 35, 42, 58, 60, 85, 86, 92, 110, 116, 122, 124, 129, 130
Decreased grievances and malpractice claims	9, 30
Monitoring, Data Collection, Continuous Feedback, Increasing Co-Creation	13, 14, 28, 45, 53, 67, 68, 103, 105, 108, 109
OUTCOMES: BETTER CULTURE	
Increased compassion	70, 71, 84, 85, 121
Improved experience	4, 5, 10, 11, 13, 17, 29, 30, 47, 49, 70, 71, 74, 76, 79, 84, 85, 92, 101, 113, 121, 123, 127, 129, 130
Improved staff retention	13, 30, 70, 71, 121
Reduced burnout/stress	16, 44, 76
Inclusive culture	31
OUTCOMES: BETTER CARE	
Care plan goals match patient goals	1, 3, 4, 17, 25, 35, 42, 63, 110, 116
Improved symptom management	34
Improved safety	15, 29, 65, 107, 114, 130
Improved transitions	26, 28
Decreased unnecessary readmissions	27, 46, 65, 120, 123, 124
OUTCOMES: BETTER HEALTH	
Improved (patient-defined) health outcomes	4, 29, 32, 34, 46, 54, 57, 61, 65, 81, 82, 93, 97, 104, 105, 115, 128
Increased patient self-management	4, 41, 62, 69, 77, 90, 100, 112, 115, 124, 128
Reduced illness burden	8
Improved quality of life	41
Reduced disparities	22
OUTCOMES: LOWER COSTS	
Appropriate health care spending	3, 30, 45, 51, 62, 76, 105, 110, 113, 120, 123, 124
Appropriate utilization and length of stay	3, 76, 113
Improved efficiency	17

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