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Innovation Series 2011

Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care

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Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care

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Executive Summary

In response to growing interest from the hospital community in better understanding and improving the experience of patients and their families during hospitalization, the Institute for Healthcare Improvement (IHI) conducted an in-depth review of the research, studied exemplar organizations, and interviewed experts in the field. Our aim was to identify the primary and secondary drivers of exceptional patient and family inpatient hospital experience (defined as care that is patient centered, safe, effective, timely, efficient, and equitable), as measured by the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey's "willingness to recommend" the hospital.[1] The project's multistakeholder team included patient and family members, patient and family advisors to health care organizations, IHI faculty, and experts in patient- and family-centered care.

The project identified five primary drivers of exceptional patient and family inpatient hospital experience of care (each with associated secondary drivers, evidence, and exemplars): leadership; staff hearts and minds; respectful partnership; reliable care; and evidence-based care. Hospitals can use this framework to design their efforts to improve the patient and family experience — testing and implementing changes, weaving them into the fabric of daily work for everyone, and achieving outstanding results.

This white paper compiles evidence and resources to support improvement of the experience of patients and their families during hospitalization.[2,3] This work has informed the IHI Improvement Map,[4] IHI initiatives such as Transforming Care at the Bedside,[5] and presentations at the IHI National Forum, along with the improvement efforts of many hospitals. Although this paper draws primarily on experiences in the US, co-authors Conway and Watson have used this work in the UK and find the content highly transferable.

Background

Increased attention to the patient and family experience of inpatient hospital care stems from several sources. First, public reporting in the US of Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)[6] provides data on all hospitals' performance and allows the public to compare organizations. Second, despite their efforts, many organizations have had trouble rapidly improving their patient and family experience results and sustaining the gains. Third, genuine and effective partnerships with patients at the clinical and organizational level are slow to develop, despite exemplars with proven results. Finally, many leaders struggle with integrating efforts to improve the patient experience into the strategic work of the hospital, treating these efforts instead as an array of good ideas.

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In the face of one or more of these challenges, hospital leaders began asking IHI urgent questions, including:

- How do we provide an exceptional patient and family experience?
- There are so many pieces to patient- and family-centered care; how do we make sense of it all?
- We have so many different projects underway; when will we start seeing real progress?
- Does improving the patient and family experience actually make a difference in outcomes?

In response, IHI initiated a 90-day research and development project to answer these and other questions. The R&D project included the following:

- A multistakeholder project team, including patient and family members;
- A review of the evidence by an expert librarian and inclusion of that evidence throughout the project to help inform the work;
- Interviews with over 60 leaders experienced in measuring and improving hospitals' patient and family experience;
- Interviews with exemplar hospitals;
- Consultations with expert organizations, including the Institute for Patient- and Family-Centered Care, the Picker Institute, and Planetree; and
- A workgroup of organizations from IHI's IMPACT Learning and Innovation Community to test and learn from proposed actions to accelerate improvement.

The aim of the R&D project was to provide a concise summary and a clear framework (in the form of a driver diagram) of what it takes to achieve a culture of patient- and family-centered care and an exceptional experience for hospitalized patients and their families. To help hospitals make sense of the many aspects of improving the patient and family experience, this white paper includes:

- **A list of primary and secondary drivers** that, taken together, will result in achieving the overall aim;
- **Exemplars** from a variety of hospitals to help translate concept into action;
- **Tips on how to get started**; and
- **Extensive references and a bibliography** to provide further evidence, guidance, and applied examples.

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Three themes emerged during the development of the driver diagram.

1. *An integrated system is key to achieving the aim of an excellent patient and family experience of inpatient hospital care.*

Interviewed leaders and experts were unable to separate efforts to improve the patient experience from efforts to improve quality and safety; they saw the two as integrated and mutually reinforcing. For example, excellent partnerships with patients contribute to safer care, and safer care results in better patient experiences. Patients and families view the experience of care in its entirety, not as separate components; thus clinical, relational, and environmental aspects of care all tie together.

2. *Leadership behavior at the executive, middle, and front-line levels is essential to achieving exceptional results.*

Leadership commitment to creating an environment that nurtures and continuously improves the patient and family experience and results in positive outcomes is essential. When executives delegate improving the patient experience to caregiving teams, results are isolated and limited. Effective leaders demonstrate the components of IHI's Framework for Leadership for Improvement: they have the *will*, *ideas*, and commitment to *execution* to achieve results.[7]

3. *The path to achieving excellence in the patient and family experience includes a group of dynamic, positively reinforcing actions rather than a linear set of activities.*

For instance, effective leadership engages the hearts and minds of staff and providers, which in turn provides a foundation for respectful team communication and partnerships with patients and families, which in turn reinforces staff and provider engagement.

Patient- and Family-Centered Care: History, Definition, and Current Status

History and Definition

References to "patient-centered care" date to the 1950s, and the concept of "patient-centered medicine" was introduced by Balint and colleagues in 1970.[8] The Picker Commonwealth Program for Patient-Centered Care and the Picker Institute began research in 1988, identifying eight essential dimensions of patient-centered care and measures of patient experience for each dimension. Dimensions included access; respect for patients' values and preferences; coordination of care; information, communication, and education; physical comfort; emotional support; involvement of friends and family; and preparation for discharge and transitions in care.[9] In 2001, the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*,[10] included patient centeredness as one of its six overarching aims for improvement. "Patient experience" is a measure of patient centeredness.[11]

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There are several definitions of "patient- and family-centered care." Although they vary slightly, the definitions offered by the Picker Institute,[12] the Institute for Patient- and Family-Centered Care,[13] and Planetree[14] share common elements (see Table 1).

Table 1. Definitions of Patient- and Family-Centered Care

The Picker Institute

- Patient- and family-centered care is defined as "improving health care through the eyes of the patient."
- All patients deserve high-quality health care and patient views and experiences are integral to improvement efforts.
- Patient-centered care includes the following principles:
  - Effective treatment delivered by staff you can trust;
  - Involvement in decisions and respect for patients' preferences;
  - Fast access to reliable health care advice;
  - Clear, comprehensible information and support for self-care;
  - Physical comfort and a clean, safe environment;
  - Empathy and emotional support;
  - Involvement of family and friends; and
  - Continuity of care and smooth transitions.

Institute for Patient- and Family-Centered Care

Patient- and family-centered care has these characteristics:

- People are treated with dignity and respect;
- Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful;
- Patients and family members build on their strengths by participating in experiences that enhance control and independence; and
- Collaboration among patients, family members, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

Planetree

Patient- and family-centered care includes the following components:

- Human interaction;
- Family, friends, and social support;
- Information and education;
- Nutritional and nurturing aspects of food;
- Architectural and interior design;
- Arts and entertainment;
- Spirituality;
- Human touch;
- Complementary therapies; and
- Healthy communities.

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Whether drawing on these definitions or others, organizations should craft a definition of patient- and family-centered care that meets their unique needs and mission. The definition provides the focus for all work to improve the patient and family experience. It should be clear, compelling, precise, and concise. It is not a slogan but an authentic statement of the organization's beliefs and promises to patients and families, with the overall intent to engage patients and their families as full partners in care and in all decision making. IHI defines "family" as those individuals the patient chooses to call family, not those that caregivers define.

Current Status

Optimizing the patient and family experience has historically been viewed as a nice-to-have, but not a fundamental aspect of a health care organization's attention. Despite nearly a half century of conversation, research, and application, realization of patient- and family-centered environments, systems, and experiences has been elusive. The *Patient-Centered Care Improvement Guide*, developed jointly by Planetree and the Picker Institute, captures and reports myths that have slowed progress (along with the evidence debunking them).[15] Sample myths include the following:

- There is no evidence to prove that patient- and family-centered care (PFCC) is effective.
- Providing PFCC is too costly.
- Providing PFCC will add more work for nurses; it will take too much time.
- The first step to PFCC is new construction (or its companion myth: We will do PFCC and have better experience results as soon as we eliminate double patient rooms).
- Patients' access to the medical record violates confidentiality requirements.
- We have won numerous quality awards, so we must be patient- and family-centered.
- The patients will have unrealistic demands.
- Families will interfere with care, creating delays, errors, and lapses in infection control.
- Having patients and families at care team meetings will inhibit staff and providers from being open.

Multiple forces, both "push" and "pull," are changing the nature of patient- and family-centered care rapidly and dramatically. These forces are summarized in Table 2.

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Table 2. Forces Impacting Patient- and Family-Centered Care

"Push" Forces: Making the Status Quo Uncomfortable	**"Pull" Forces: Making the Future Attractive**
• Consumer movement: ❍ Consumers are saying to health care professionals, "It isn't yours alone to decide." ❍ Patient rights • Patient safety: ❍ The voices and faces of those who have been harmed by medical care are more visible to hospital boards and consumers. ❍ Agency for Healthcare Research and Quality consumer patient reporting system • Transparency demands • Health care reform • Accrediting organizations • AARP, Consumer Reports, National Quality Forum, National Priorities Partnership, Picker Institute, Planetree, Institute for Patient- and Family- Centered Care, IHI, Lucian Leape Institute, World Health Organization — all working to advance consumer partnerships	• Organizing the health care system around the patient and family works for everyone. • Optimizing the patient experience correlates with other outcomes, including clinical,[16,17] financial,[18] and staff satisfaction. • Patient activation and self-management is enhanced, achieving better chronic disease outcomes.[19,20] Great stories and results are being generated internationally and in health care organizations within the US, shaping a new standard for performance. • Health care providers and caregivers are seeking a better patient experience for those they serve and for their own families.

A growing body of evidence shows that improving the patient experience and developing partnerships with patients are linked to improved health outcomes. For example, evidence shows that patients who are more involved in their care are better able to manage complex chronic conditions,[21,22,23] seek appropriate assistance, have reduced anxiety and stress,[24] and have shorter lengths of stay in the hospital.[25] In addition, the Centers for Medicare & Medicaid Services (CMS) has supported posting patient experience ratings on the Hospital Compare website[26] and announced that future reimbursement will be impacted by a hospital's ranking relative to its peers. This combination replaces the "nice-but-not-necessary" view of PFCC; hospital leaders now have performance requirements in patient and family experience equal to those in clinical quality, safety, and finance.

Understanding the Exceptional Patient and Family Experience

While extensive literature exists on the patient experience, organizations often struggle with where to begin the journey, what is the right sequencing, how to intensify progress when results are lagging, and which actions yield the best results when an abundance of recommendations exist. Evidence from the literature, successful organizations, and content experts offers a clear picture of essential actions for application, further testing, and, where appropriate, broader spread:

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- Partnerships with patients and families are the foundation of excellence in PFCC. As noted by the Lucian Leape Institute of the National Patient Safety Foundation, "If health is on the table, the patient must be at the table, every table."[27]
- An exceptional patient and family experience is the common ground for all six aims of quality care as defined by the Institute of Medicine in *Crossing the Quality Chasm* — care that is patient centered, safe, effective, timely, efficient, and equitable.[28]
- Patient- and family-centered care must be part of all settings of health and health care (inpatient, outpatient, extended care, and home care) and all levels (environment, organization, microsystem, and individual experience of care). (See Table 3.)
- Isolated actions to improve patient and family experience will provide localized results, with little transfer to the entire experience across all settings and limited sustained results.
- A strong and growing evidence base shows that patient- and family-centered care is not only a fundamental value, but also essential in the improvement of clinical, financial, service, and satisfaction outcomes.[29,30]

Table 3. Patient- and Family-Centered Care at Various Levels

Level	**Location**	**Examples**
Environment	Community, Region, State	• Community groups • Care coordination across organizational boundaries • Accountable care organizations, medical homes • Advanced care planning (e.g., Medical Orders for Life Sustaining Treatment [MOLST]) • School and church programs • Public health and other consumer campaigns
Organization	Health System, Trust (UK), Hospital, Nursing Home	• Patient experience surveys, patient complaints • Patient and family councils, advisors, faculty • Resource centers, patient portals • Access to help and care 24/7 • Medication lists
Microsystem	Clinic, Ward, Unit, Emergency Department, Delivery	• Parents, advisors, and advisory councils • Open access, optimized flow • Family participation in rounding
Individual Experience of Care	Bedside, Exam Room, In the Home	• Access to the patient record • Shared care planning • "Smart Patients Ask Questions"[31]

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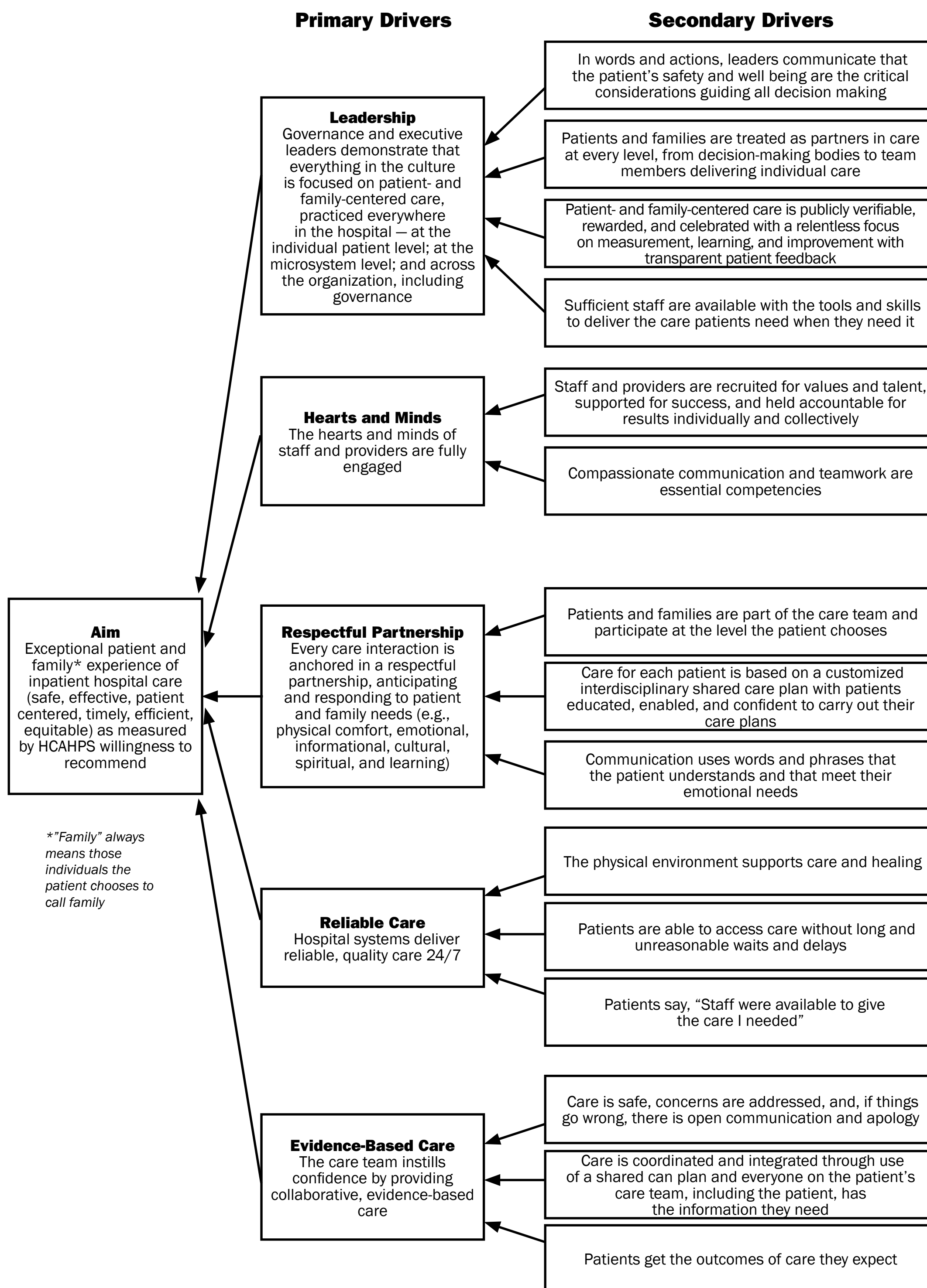
IHI Patient and Family Experience Driver Diagram



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The IHI Patient and Family Experience Driver Diagram provides a visual overview of three things:

1. **Aim**: An exceptional patient and family experience
2. **Primary drivers**: Essential actions to achieve the aim
3. **Secondary drivers**: Steps on the path to achieve the primary drivers

A driver diagram helps organize theories and ideas that, when implemented, may result in improvement to achieve a specific goal or outcome. To achieve the desired outcome, primary drivers (essential actions) and secondary drivers (specific change ideas associated with each primary driver) are identified.

The primary drivers are as follows:

- **Leadership**: Governance and executive leaders demonstrate that *everything* in the culture is focused on patient- and family-centered care, practiced everywhere in the hospital — at the individual patient level; at the microsystem level; and across the organization, including governance.
- **Hearts and Minds**: The hearts and minds of staff and providers are fully engaged through respectful partnerships with everyone in the organization and in a commitment to the shared values of patient- and family-centered care.
- **Respectful Partnership**: Every care interaction is anchored in a respectful partnership, anticipating and responding to patient and family needs (e.g., physical comfort, emotional, informational, cultural, spiritual, and learning).
- **Reliable Care**: Hospital systems deliver reliable, quality care 24/7.
- **Evidenced-Based Care**: The care team instills confidence by providing collaborative, evidence-based care.

Primary Driver #1: Leadership

> *Governance and executive leaders demonstrate that* ***everything*** *in the culture is focused on patient- and family-centered care, practiced everywhere in the hospital—at the individual patient level; at the microsystem level; and across the organization, including governance.*[32]

As demonstrated in IHI's Framework for Leadership for Improvement,[33] *Seven Leadership Leverage Points* white paper,[34] "Boards on Board" How-to Guide,[35] health care leadership studies,[36] and the experience of exemplars, improvement of the patient and family experience requires the active engagement of leadership.

Effective leaders focus the organization's culture on the needs of patients and families (i.e., providing care that is patient-centered, rather than provider-centered), tap into innovative ideas, and have the persistence and skills to create a PFCC culture.[37,38,39] Leaders from executives to front-line managers share a commitment to this goal, and understand that it is led by senior leaders and is part of the organization's core strategy. Moreover, it applies to all work — from how care is provided to housekeeping, the finance department, parking services, and environmental design. Everyone is a caregiver.

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These leaders are eager to understand the unwritten rules that need to be rewritten to provide a better patient experience. For example, one manager challenged the rule that patients needed to wear hospital attire when they preferred their own clothes. Her actions illustrate the growing experience in exemplars that the powerful combination of senior, middle, and front-line leaders is essential in accelerating improvement. One CEO invited staff members who were recently hospitalized or had a loved one hospitalized to talk with him about their experiences. He asked them, "What rules did you have to break to get the care you wanted?" Another senior executive declared that all hospitals in an entire system would achieve patient-determined visitation within 90 days. She then worked with hospital managers and staff to develop the infrastructure and support systems to make elimination of traditional visiting hours a reality.

Governance members demonstrate their leadership through one of the six essential things boards should do, as described in IHI's "Boards on Board" How-to Guide — *Getting Data and Hearing Stories*: Select and review progress toward safer care as the first agenda item at every board meeting, grounded in transparency, and putting a "human face" on harm data.

Many boards now start their meetings with a review of a patient who experienced harm at their hospital in the prior month. These cases provoke new and deeper conversations, and provide added will to move to safer systems.

Another example of governance leadership for patient- and family-centered care is case study review. The CEO, with the assistance of the Chief Medical Officer (CMO) and Chief Nursing Officer (CNO), conducts a detailed, personal investigation of a significant patient injury in the hospital, including interviewing the involved patient, family, and staff. The purpose is to understand in great depth the "story," in all of its complexity, in order to illuminate the nature and sources of hazard in a complex health care organization. The CEO personally presents that case to the board in a session of no less than one hour in length. If possible and desirable, the affected patient and family are present at the board meeting to add their accounts and perspectives in person.

Secondary Drivers

Secondary drivers are steps on the path to achieve the primary drivers. The core concepts are that the actions of senior leaders must match their words; senior leaders must be highly visible in meaningful ways; and they must closely engage patients and families in the work of the organization at all levels.

- In words and actions, leaders communicate that the patient's safety and well being are the critical considerations guiding all decision making.[40]
- Patients and families are treated as partners in care at every level, from decision-making bodies to team members delivering individual care.[41,42]
- PFCC is publicly verifiable, rewarded, and celebrated with a relentless focus on measurement, learning, and improvement with transparent patient feedback.[43]

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- Sufficient staff are available with the tools and skills to deliver the care patients need when they need it.[44]

Exemplar

In 2004, Spectrum Health System began using a national comparative patient experience survey tool. Leaders were dismayed to see that patients' assessments of their experiences were much lower than they had assumed — the 24th percentile. These results led to steps by leaders and the entire organization that improved the patient and family experience dramatically over the next four years. This multi-year plan became the culture of the organization — not a "program" or an "initiative." Spectrum Health System's patient experience results are now above the 80th percentile. Spectrum Health System vice president of innovation and patient affairs, Kristine White, described key actions that led to these results:

- "**All in**": All leaders define and own the commitment to PFCC and excellence in patient and family experience. An executive is accountable for the strategy and execution on behalf of the senior management team; however, all leaders play key roles in owning the outcomes. For example, the CFO can talk about the overall PFCC strategy as knowledgeably as the accountable executive, and beyond that, can describe the work in patient-friendly billing systems. The president reserves the first agenda item at every monthly management meeting for PFCC stories of impact, success, and opportunities for improvement.
- **PFCC is linked to the Spectrum Health mission**: Senior leaders aim high in achieving PFCC results, aligned with other key strategies through a combination of local and organization-wide efforts.
- **Patient experience is deeper than solely a focus on service**: Service skills are necessary but not sufficient to create a PFCC culture. PFCC is not about "being nice"; it is about system changes to enable excellent partnerships.
- **Focus on impact**: The focus is on processes that are meaningful to patients and families, not on an abundance of activities that do not add value.
- **Family presence is essential to a multidisciplinary team**: For example, visiting hours and restrictions were eliminated throughout the entire system in 90 days. Instead of predetermined "visiting hours," family presence is based on the needs of each individual patient. Leaders worked with staff to ensure that the infrastructure, processes, and resources were in place to achieve a successful outcome. Staff worked with patients to manage unique challenges such as semi-private rooms.
- **Involvement of patient and family advisors in executive and service line councils throughout the organization**: In eight hospital settings, there are approximately 100 patient and family advisors for more than 140 service sites and 2,000 beds system-wide. An Executive Council includes core patient advisors, service line council chairs, and members of the executive team; patient and family advisors participate on interview teams for key hospital positions and on key committees (e.g., Board Quality and Safety Committee, Patient Safety Committee, Michigan STate Action on Avoidable Rehospitalizations [MiSTAAR] initiative, and a system-wide patient education council).

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- **Development of PFCC skills**: For example, first-year medical residents participate in simulations of patient- and family-centered care interactions.
- **Focus on strategies to engage the hearts and minds of staff members**: The goal is for each staff member to understand clearly how every person's actions ultimately affect the patient and family.

Primary Driver #2: Hearts and Minds

The hearts and minds of staff and providers are fully engaged.

PFCC cannot simply be mandated; people working in health care must feel supported in order to be empathic and compassionate care providers. While the technical details of health care may be more complex to evaluate, the patient's overall experience is highly linked to the quality of all interactions with caregivers — and exemplar organizations view everyone as caregivers. Len Berry refers to customers as "detectives" when they interact with health care organizations, consciously and unconsciously filtering "clues" embedded in their experience and organizing them into a set of impressions.[45,46] His studies show that the more significant, variable, complicated, and intimate the service, the more attuned customers are to clues. Health care clearly has all four of these characteristics. The clues indicate why creating an excellent patient and family experience is a result of a well-designed system, not just an isolated set of activities.

Berry describes three sets of interdependent clues (renamed here to suit the health care setting):

- **Clinical**: The *what* of service — its technical quality, the competence of the providers, its reliability, and its coordination. Patients and families vary widely in their ability to assess the clinical components of care; however, they can assess how well care team members work together, communicate with one another, and convey a sense to patients that "I know you." This clue is considered the pass/fail of an experience. An exceptional experience is difficult to achieve when the patient is signaled at many steps that technical quality, competence, reliability, and coordination are deficient.
- **Environmental**: The physical aspects of *how* the service is delivered. The first impression for the patient and family, as well as for caregivers, signals the type of experience they will have. Health care environments can easily cause undue stress; alternatively, they can offer a sense of calm, hope, and healing. Organizations that pay attention to the details signal in many ways that *we are here to care for you*. Noise, lighting, ease of finding your way (or staff members eager to help you find your way), cleanliness, orderliness, comfortable settings, and staff appearance all provide clues about the experience — positive or negative.
- **Relationship**: Interactions based in respect, addressing the patient and family's emotional needs, are an important determinant of the patient and family experience. Actions that engender trust, including efforts to meet the patient's emotional needs, signal that *this is an excellent place to be*. Respectful, empathic relationships in combination with clinical quality are essential to achieving exceptional experiences.

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Staff and providers are more effective in their work, provide safer care, and can achieve better patient and family experience if they find a match between their personal values and those of the organization, are supported by effective systems, and are recognized for the work they do.[47] Several measurement tools offer robust means of gauging workforce engagement, better than employee satisfaction alone, and are increasingly used in high-performing hospitals to understand the level of trust and commitment to the organization.[48]

Organizations that are recognized as best employers and achieve outstanding patient and family experience understand that hiring for fit with values is an essential first step. Leaders are responsible for systems to recruit, select, develop, and retain people who share the commitment to outstanding patient and family experience.

Secondary Drivers

- Staff and providers are recruited for values and talent, supported for success, and held accountable for results individually and collectively.
- Compassionate communication and teamwork are essential competencies.

Exemplar

Griffin Hospital, the nation's first Planetree Hospital, has been listed on *Fortune* magazine's "100 Best Companies to Work For" for ten years in a row. Griffin has been recognized for providing superior patient care, defined as exceptional clinical outcomes in the top one percent of all hospitals in the United States. Griffin exemplifies engaging the hearts and minds of staff and providers. Peers participate in hiring new employees, using behavior-based interview questions that ask people to describe behaviors — for example, "Share a time you felt you were providing patient-centered care."

Griffin demonstrates its commitment to developing a common vision consistent with the personal values of employees by supporting staff members in achieving their professional aspirations and personal goals. Griffin achieves this in many ways: hiring people who are committed to their mission of exceptional care, providing clear expectations at orientation, and supporting ongoing development. After one staff retreat that focused on the whole person, not just who they are at work, one staff member commented, "I personally feel the course made me take a look at my life, personally and professionally, and made me rethink what is really important. I have made a few adjustments, and feel much happier and more at peace with my life."

Griffin Hospital leadership and executives successfully engage staff by addressing the meaningfulness of work, developing staff personally and professionally, and building healthy interpersonal relationships. Notably, rates of pay at Griffin are lower than those at surrounding organizations. This illustrates Deming's contention that "Joy in work is all anyone asks for."[49]

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Primary Driver #3: Respectful Partnership

> *Every care interaction is anchored in a respectful partnership, anticipating and responding to patient and family needs (e.g., physical comfort, emotional, informational, cultural, spiritual, and learning).*

At the core of the exceptional patient and family experience is a respectful partnership based on enabling patients and families to participate in care at the level they choose. Caregivers understand that they are guests in the patient's life and view every interaction as an opportunity to learn more together to achieve better health.[50,51] Support of the patient's and family's emotional needs is highly linked to a positive experience. Staff and providers' skills in understanding and meeting the patient's emotional needs are essential to creating an excellent experience of care.[52,53]

Respectful interactions are multidimensional, addressing physical comfort, emotional needs, and informational requirements grounded in the patient's and family's cultural, spiritual, and unique learning needs, including health literacy. People choose to participate in their care at different levels, with different preferences. Respecting and responding to each individual is an important part of the patient experience. Furthermore, patients' levels of understanding about health care terminology and what it means for their health vary widely. Understanding the health care literacy level for the individual is the foundation of a respectful partnership.[54]

A landmark publication by the Institute of Medicine, *Health Literacy: A Prescription to End Confusion*, defines health literacy as "The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."[55] The Institute's definition goes on to recognize the social context of health decision making, where health care communication is based on the interaction of the individual's skills with health contexts and with broad social and cultural factors at home, at work, and in the community. This definition of health literacy provides a foundation to build on for respectful partnerships.

Secondary Drivers

- Patients and families are part of the care team and participate at the level the patient chooses.[56,57,58]
- Care for each patient is based on a customized interdisciplinary shared care plan with patients educated, enabled, and confident to carry out their care plans.[59]
- Communication uses words and phrases that the patient understands and that meet their emotional needs.[60]

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Exemplars

In 2003, Iowa Health System established the Health Literacy Collaborative, a multidisciplinary group committed to learning, sharing, and implementing improvements in health literacy. The Health Literacy Collaborative incorporates clinical performance improvement experts, health literacy teams, and "New Readers of Iowa" ambassadors — adults who learned to read as adults. This collaboration has introduced, implemented, and built system-wide capacity in using a variety of health literacy-related interventions, including Ask Me 3,[61] the Teach Back method,[62] and reader-friendly print materials.

Children's Hospital of Philadelphia offers an outstanding example of deep and active partnership with patient and families in teaching health professionals. Leadership Education in Neurodevelopmental Disabilities (LEND) is an interdisciplinary leadership training program with trainees and staff in Audiology, Developmental-Behavioral Pediatrics, Family Leadership, Health Care Administration, Nursing, Nutrition, and Occupational Therapy. The program's primary objective is to support expert interdisciplinary clinical and leadership training to graduate- and post-graduate-level fellows from diverse health care disciplines. Faculty partner with advocates, representatives from community agencies, and parents to provide this training and to improve the health infrastructure for children with disabilities and their families, with a special emphasis on shared care plans for children with chronic conditions. Family advocates actively teach health professionals effective partnership behaviors.

At Virginia Mason Medical Center's critical care unit, multidisciplinary rounds (MDR) that include the family have taken place at the patient's bedside since 2004. Families have been invited to be part of the nursing shift report since 2008. Bedside MDRs are now standardized, with a focus on the biomedical issues and the aim to recalibrate the daily plan of care. Families are invited and encouraged to be present. Team members help to "set the agenda" for families (and patients, if they are able) by describing the process, explaining the aim of rounds, welcoming their presence, acknowledging that they may have many questions, and explaining that, because of the rounding schedule, there will be time for questions. If there isn't time to answer all questions, the MDR team schedules a time to address the questions.

The MDR team then asks patients and families if they want to participate. For a few patients, the team members are not in the room: those who request that rounds take place outside the room, those for whom the team's presence clearly causes undue stress, and those in contact isolation. Requests and stress rarely are issues; contact isolation is more frequent. Separate patient and family meetings for goal setting that may include discussion of end-of-life issues are scheduled for specific additional time. Agenda setting is also done when family are present for the nursing shift report. Nurses and physicians have not found that the families' presence slows the process; on the contrary, physicians have learned that the open, transparent MDR process saves time.

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Primary Driver #4: Reliable Care

Hospital systems deliver reliable, quality care 24/7.

Reliable systems convey a sense of clear, well-organized care in which all care team members, including the patient and family, know how they work and fit together, particularly when patients participate in designing services.[63] Unreliable systems result in what one patient advisor on the IHI patient experience research and development team described as, "We fall through the cracks."

Positive leadership behaviors, engaged staff and providers, and respectful interactions can be quickly undermined by systems that leave patients and families confused, unheard, or even harmed. Reliable care is part of the integrated system required to achieve excellence in the patient and family experience.[64,65] This extends to the physical environment, with its importance in generating confidence in health care provision and aid to healing.[66]

Secondary Drivers

- The physical environment supports care and healing.[67]
- Patients are able to access care without long and unreasonable waits and delays.
- Patients say, "Staff were available to give the care I needed."[68]

Exemplar

In efforts to improve reliable care, senior executives at Baptist Memorial–North Mississippi, a 217-bed hospital, partner with patients and families by hosting patient safety lunches every other week. Under the leadership of the CNO, staff give invitations to patients and families the day before the lunch. Senior leaders welcome participants and explain the purpose: to ensure safe care. The leaders start by telling the Josie King story,[69] then explain two examples of efforts underway at North Mississippi to improve the safety of care: "Ticket to Ride," a system for safe transitions from one department to another; and "Condition H," a system that encourages a family member to call for assistance if they have concerns about their loved one. These two systems have been underway for over a year, and the response has been very positive. Family members (and a few patients) are able to share their stories, help hospital leaders to improve reliable care by providing a view of care only patients and families have, and hear about the efforts underway to improve care.

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Primary Driver #5: Evidence-Based Care

The care team instills confidence by providing collaborative, evidence-based care.

Patient and family advisors as well as leaders view evidence-based care as essential to an excellent experience. As one patient noted, "If I don't get the right care, how can I say I had a great experience?" Evidence-based care is grounded in best known science combined with expert judgment, and is increasingly guided by patient values.[70] Patients expect that providers and staff will use the best known science or evidence-based medicine, just as people expect a safe arrival when they travel by airplane. From the view of the patient and family, evidence-based care also includes what happens when things go wrong,[71] how care is coordinated across sites,[72] and the predictability of outcomes.[73]

Organizations should develop and introduce advances in health information technology and new devices using a PFCC lens, so as to enhance improvements in the patient experience. Significant advancements are possible when knowledge of care needs from the patient and provider viewpoints guide the design and implementation of health information technology.[74] For example, it is common for there to be a caregiver learning curve when new technology is introduced; however, the patient experience is not enhanced nor is confidence instilled when they are asked to "please be patient as we implement our new electronic medical record."

Secondary Drivers

- Care is safe, concerns are addressed, and, if things go wrong, there is open communication and apology.[75]
- Care is coordinated and integrated through use of a shared care plan, and everyone on the patient's care team, including the patient, has the information they need.
- Patients get the outcomes of care they expect.

The secondary driver, "Patients get the outcomes of care they expect," derives from patient and family advisors and the literature. It has generated concerns from providers who state that they often do not know the outcomes a patient expects, or that the provider's expectations about outcomes may differ from the patient's expectations. This step reflects the view that the patient, family, and caregivers will have a shared care plan that includes the expected outcomes, including when a provider does not fully know what outcomes to expect. One gap in shared outcomes is hospital-acquired complications — for example, infections or deep vein thrombosis — which patients do not expect in the course of care. When the shared care plan is lacking or when caregivers review risks in terms patients and families do not understand, the result is often outcomes patients do not expect.[76]

Another example comes from a patient and family advisor who observed, "I am a breast cancer survivor. I know not everything is known or predictable and that there will be surprises in the course of my care. I want to know that if it is a surprise for me, it is also a surprise for my provider — that

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we have a shared understanding of the care plan and we both know what is going on."

The second concern that arises is, "What if the patient has unreasonable demands or expectations?" This is a widely held concern of busy caregivers who strive to meet many competing demands in their work. However, experiences of top-performing organizations challenge this belief. Patient and family expectations are almost always straightforward and aligned with the mission of those working in health care. The following is a list of what patient advocates want 100 percent of the time:[77]

- To be listened to, taken seriously, and respected as a care partner
  - To have my family and caregivers treated the same
  - To participate in decision making at the level I choose
- To be always told the truth
  - To have things explained to me fully and clearly
  - To receive an explanation and apology if things go wrong
- To have information communicated to all my care team
  - To have my care documented in a timely and impeccable way
  - To have these records made available to me if requested
- To have coordination among all members of the health care team across settings
- To be supported emotionally as well as physically
- To receive high-quality, safe care

Health professionals agree with these expectations, but often lack the systems to ensure that they are met reliably.

Providers and patients who understand each other in the caregiving relationship will come to more consistent agreement about the care plan, save time, and have fewer irreconcilable differences.[78,79] However, a small number of patients and families can be challenging for staff and providers to partner with. Leading organizations avoid further deterioration and stress for everyone by ensuring that supportive infrastructures are in place to aid in working with challenging family and social dynamics rather than leaving caregivers to struggle unassisted. Timely access to skilled support prevents escalation of concerns for patients, families, and caregivers.

Exemplar

The University of Pittsburgh Medical Center (UPMC), highlighted in a HCAHPS User Group Profile on *High-Performing and Patient- and Family-Centered Academic Medical Centers*,[80] combines evidence-based care with exceptional experience through their Patient- and Family-Centered Care Methodology. Initiated in their orthopedic program, they now use this methodology extensively. They observe the entire patient experience in a care setting or program, involving all team members who have touch-points with the patient. The UPMC team is able, through this in-depth look, to see all the aspects of the patient journey that influence the patient and family experience of care. This focus

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on the front-line caregivers' interaction with patients and families provides a means of discovering what barriers exist that may prevent caregivers from providing care that is coordinated and integrated across boundaries, and an opportunity to address those barriers, often with innovative solutions.

The steps in UPMC's PFCC Methodology include the following: 1) select a care experience, 2) establish a PFCC experience guiding council, 3) understand the current state of care experience through a variety of means, but always with direct observation of the journey from the patient's view (including patient storytelling and existing survey data), 4) develop a PFCC workgroup based on the patient touch-points, 5) with the PFCC workgroup, create a shared vision of an ideal experience based in telling the story of what that personally looks and feels like, and 6) identify where improvements are needed and begin making improvements.

As a result of this approach, patients have safe care — for example, the joint infection rate is 0.3 percent. The operating room team coordinates their work so tightly that ten complete hip or knee replacements are performed in a seven-hour period. Patients have the outcomes they expect and are delighted by the service, as evidenced by consistent excellence in the HCAHPS results.

Measures

Measures to show progress towards achievement of primary and secondary drivers, and ultimately improved patient and family experience, are tailored to unique organizational needs. The measures include a mix of process and outcome metrics linked to the aims for each secondary driver. The measures are developed based on the starting point of each department and organization. Table 4 presents examples of measures of patient and family experience.

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Table 4. Sample Measures of Patient and Family Experience

Primary Driver	Secondary Driver	Measures
#1: Leadership	Patients and families are treated as partners in care at every level.	• A Patient- and Family-Centered Care Assessment is completed with key stakeholders from across the organization and with patient and family advisors. • A workplan is developed to address gaps. • There is measureable closure of gaps.[81]
#2: Hearts and Minds	Staff and providers are recruited for values and talent, supported for success, and accountable individually and collectively for results.	• Employee and provider engagement survey results show steady improvement in overall engagement results; organizations focus on questions such as those found in the Gallup Q12 (see Table 5).[82]
#3: Respectful Partnerships	Care for each patient is based on a customized interdisciplinary shared care plan with patients educated, enabled, and confident to carry out their care plans.	• 100% of patients have a shared care plan in place, with evidence of active patient and family participation. • 100% of nurses effectively use Teach Back. • 100% of all patient education materials meet health literacy guidelines for appropriate reading level.
#4: Reliable Care	Patients are able to access care without long and unreasonable waits and delays.	• See the IHI Improvement Map process titled Patient Flow for Efficiency and Safety for measures.[83] • Use existing safety measures for reliable processes.
#5: Evidence-Based Care	Care is coordinated and integrated through use of a shared care plan, and everyone on the patient's care team, including the patient, has the information they need.	• See the IHI Improvement Map for Effective Processes.[84]

Organizations may use tools such as the Gallup Q12 (see Table 5) to assess employee engagement. The tool provides information about employees' experience in providing care and service. It also signals systems that impair the employee's ability to focus on the patient experience. Successful organizations recognize that engaged employees precede improvements in patient experience. The questions can be posed as part of an employee engagement assessment every 6 to 12 months.

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Table 5. The Gallup Organization 12 Questions (Q12) to Assess Employee Engagement

1. Do you know what is expected of you at work?
2. Do you have the materials and equipment you need to do your work right?
3. At work, do you have the opportunity to do what you do best every day?
4. In the last seven days, have you received recognition or praise for doing good work?
5. Does your supervisor, or someone at work, seem to care about you as a person?
6. Is there someone at work who encourages your development?
7. At work, do your opinions seem to count?
8. Does the mission or purpose of your company make you feel your job is important?
9. Are your associates (fellow employees) committed to doing quality work?
10. Do you have a best friend at work?
11. In the last six months, has someone at work talked to you about your progress?
12. In the last year, have you had opportunities at work to learn and grow?

Getting Started

Table 6 offers suggestions for where to begin with achieving an exceptional patient and family experience of inpatient hospital care. The goal is to have a shared vision of PFCC that provides the unifying force for everyone in the organization as well as for patients and families, and then develop systems to remove barriers to realizing that vision. Additional actions for getting started can be found in *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*.[85]

Table 6. Getting Started with Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care

Primary Driver #1: Leadership *Governance and executive leaders demonstrate that* ***everything*** *in the culture is focused on patient- and family-centered care, practiced everywhere in the hospital — at the individual patient level; at the microsystem level; and across the organization, including governance.*	• Form a multidisciplinary Steering Committee that includes patient and family members. • Develop your organization's definition and aspiration for PFCC in partnership with patients and families. • Complete a Patient- and Family-Centered Care Assessment.[86] • Use the driver diagram to identify work already underway and gaps. • Use the driver diagram assessment to identify next steps; co-develop or test strategic goals, implementation plans, and program designs with patient and family advisors. • Have patients and family members share their stories at board meetings. • Add patient and family advisors to planning teams and improvement committees. • Make sure leaders clearly communicate PFCC strategy and link it to daily work, especially quality and safety improvement. • Make sure all leaders ask, "What will we do to ensure patients are involved in this program design or this change?" "What do our safety culture results say about us as leaders, and how we balance competing demands of safety and productivity?"

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Primary Driver #2: Hearts and Minds *The hearts and minds of staff and providers are fully engaged.*	• Ensure that all employees are considered caregivers. • Evaluate Human Resource systems for hiring for PFCC values and talent through behavioral-based interviews using patient- and family-centered questions to understand the skills of the candidate in essential interpersonal competencies, especially teamwork. • Provide effective first-line manager development to ensure reliable systems for caregivers. • Identify systems that remove barriers between staff and patients and families (e.g., comfort rounds, bedside transition reports). • Make data on measures of patient and family experience rapidly available to caregiving staff — weekly or monthly, at a minimum. • Ensure that respectful behavior is expected and demonstrated by all. • Continually develop and enhance teamwork skills for staff and providers.
Primary Driver #3: Respectful Partnerships *Every care interaction is anchored in a respectful partnership, anticipating and responding to patient and family needs (e.g., physical comfort, emotional, informational, cultural, spiritual, and learning).*	• Ensure that respectful behavior is expected of all and demonstrated by all. • Make sure caregivers have health literacy expertise; use Teach Back and other effective teaching methods. • Ask patients how they want to participate in their care. • Provide patients and families with direct access to their medical records in either paper or electronic form. • Use a shared care plan to enable caregivers and patients to partner in care.
Primary Driver #4: Reliable Care *Hospital systems deliver reliable, quality care 24/7.*	• Follow a patient's journey.[87] • Ensure system reliability; reduce waits and delays, cycle times. • Incorporate key elements from Planetree and the Center for Healthcare Design into all facility design; begin with HCAHPS hospital experience questions.
Primary Driver #5: Evidence-Based Care *The care team instills confidence by providing collaborative, evidence-based care.*	• Provide evidence-based care;[88] build on current activities. • Have the board endorse a policy of full transparency and apology when things go wrong; have senior leaders enact the policy. • Ensure that patients and families know the course of care and expected outcomes.

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Conclusion

The suggested actions in Table 6 can help hospitals begin to create and continuously improve meaningful and productive partnerships with patients and families. Hospitals can use the framework described in this paper to design their efforts to improve the patient and family experience of inpatient hospital care, focusing on five primary drivers of that experience: leadership, hearts and minds, respectful partnerships, reliable care, and evidence-based care. When everyone involved in care is focused on how to have better partnerships with those we serve, and processes are put in place to support such partnerships, the experience of patients and families — and health care outcomes — will improve.

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