NATIONAL
QUALITY FORUM

Patient and Family Engagement Action Pathway: Fostering Authentic Partnerships between Patients, Families, and Care Teams

July 31, 2014

In 2014 the National Quality Forum convened a multi-stakeholder action team to focus on promoting patient and family engagement in healthcare settings through a model of sharing best practices and aligning public- and private-sector patient safety efforts. In support of the Partnership for Patients initiative, this action team brings together critical thought leaders and both local and national change agents in the field of patient and family engagement to identify aspirational goals and key strategies to drive system-level change. The results of this work will contribute to a broader national effort to authentically engage patients, families, and caregivers at all levels of the healthcare system.

Background

In March 2011, the Department of Health and Human Services (HHS) released the National Quality Strategy (NQS) and identified six priorities to achieve the overarching triple aim of healthy people and communities, better care, and affordable care. One of the six NQS priorities specifically calls us to "ensure that each person and family is engaged as partners in their care" by improving patient, family, and caregiver experience of care related to quality, safety, and access across settings; in partnership with patients, families, and caregivers—and using a shared decision making process—developing culturally sensitive and understandable care plans; and enabling patients and their families and caregivers to navigate, coordinate, and manage their care appropriately and effectively.

In support of the NQS, HHS launched the Partnership for Patients initiative to advance the priority areas of safety, care coordination, and patient and family engagement and to achieve two important goals:

1. Decrease preventable hospital-acquired conditions by 40 percent compared to 2010.
2. Decrease preventable hospital readmissions by 20 percent compared to 2010.

To achieve broad stakeholder engagement around these goals, HHS requested the National Quality Forum (NQF) to convene critical thought leaders and organizations to identify high-leverage strategies for change around the issue of patient and family engagement. NQF's Patient and Family Engagement (PFE) Action Team supports the broader Partnership for Patient goals around patient safety by harnessing the power of patients and families to be patient safety advocates, and by partnering with health care organizations to encourage person-centered care as an organizational core value. Research increasingly shows that "engaging patients and families as respected partners can improve the safety of care and…this should drive an organization's mission and strategies for individual settings of care."[1] NQF's action team supports the Partnership for Patients' approach and specific metrics for patient and family engagement, in particular, its emphasis on authentic engagement, identifying and spreading best practices, and partnering (or "team"-ing) to accomplish the goals.

A recent Health Affairs article provides a framework for this work and details three levels of engagement: direct care, organizational design and governance, and policy making.[2] Although action team members currently operate across these levels in their work, the team's focus is specifically focused on the redesign of systems and practices within the second of these levels, and is working together to create a shift in the way that families are welcomed and engaged in organization-wide systems and processes. This is similar to the Partnership for Patients best practices and metrics, which emphasize point of care, policy and protocol, and governance—the action team's focus is best categorized as "policy and protocol".

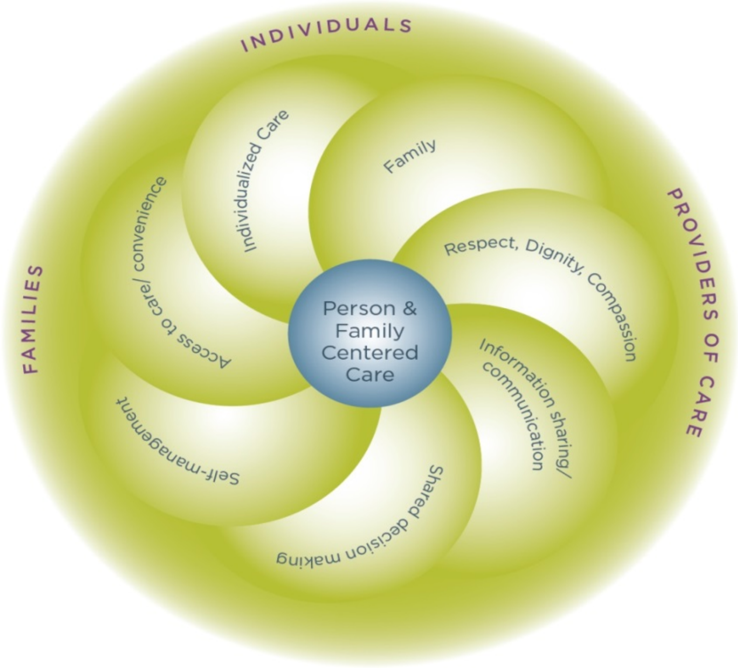
Anchoring Healthcare in Patient and Family Preferences

The multi-stakeholder PFE action team includes patients and consumer advisors, as well as representation of purchasers, health plans, and healthcare providers, including nurses, social workers, physicians, and hospital administrators dedicated to patient and family engagement (see roster in Appendix A). The team is led by Pat Mastors of the Patient Voice Institute, a leading patient and consumer advisor, and Susan Frampton, President of Planetree, a leader in advancing person- and family-centered care.

The vision of this action team is to trigger a shift throughout U.S. healthcare systems to focus on patient and family needs and preferences. Often, the patient voice is lost in the din of activity that happens in the healthcare environment. While this is not necessarily intentional on the part of healthcare providers or system administrators, it will take a concerted effort from every person providing care to profoundly change the system so that patients and their families truly feel that their needs, goals, and preferences are a primary focus. For this reason, the biggest emphasis of the action team is on *partnership*.

The action team has used two working definitions of patient-centered care. The first was published by the Institute of Medicine, and emphasizes the provider's responsibility to "[provide] care that is respectful of and responsive to individual patient preferences, needs, and values and [ensures] that patient values guide all clinical decisions…"[3] The second definition guiding the team was created by Angelica Thierot, the founder of Planetree, Inc., and it emphasizes the responsibility of the patient: "We should all demand to be treated as competent adults, and take an active part in our healing. And we should insist on hospitals meeting our human need for respect, control, warm and supportive care, a harmonious environment and…a truly healing environment."[4] More recently, an NQF project focused on identifying gaps in performance measurement related to person- and family-centered care identified core concepts to guide measure development as illustrated in Figure 1.

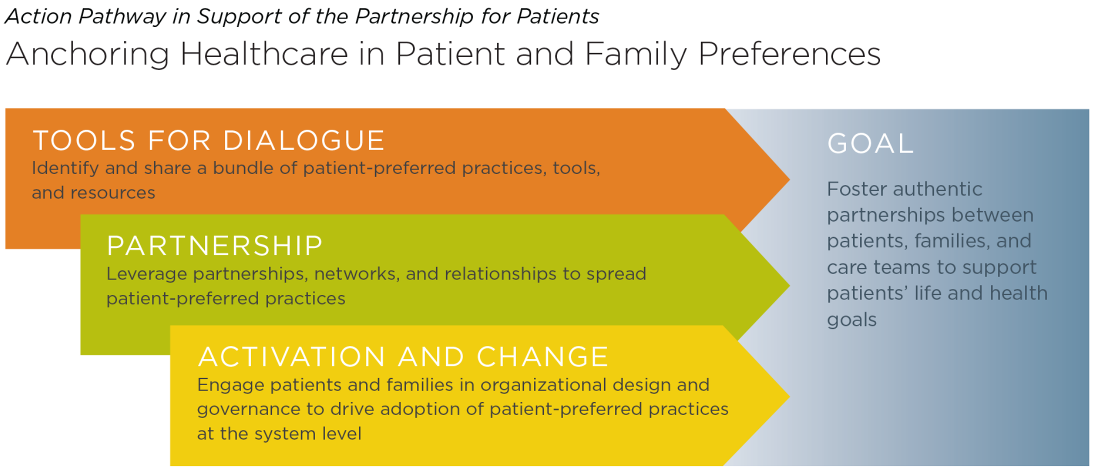
Figure 1. Person- and Family-Centered Care Core Concepts



The relationship between the above definitions and the core concepts signifies the importance of dialogue and partnership between patients, families, and healthcare teams. These are the key elements that the action team believes are missing—and yet so crucial to develop and spread. Patients must be empowered to be their own patient safety advocates; to engage in meaningful dialogues about their preferences for care; and to demand better information about discharge processes, medications, and follow-up care to promote long-term healing and prevent hospital-acquired conditions, medical errors, and unnecessary readmissions.

To accomplish this goal of authentic partnership between patients, families, and care teams, the action team is employing three strategies. The first is to identify tools, resources, and practices that reflect patient-preferred practices, and encourage meaningful dialogue. The second is to leverage existing networks and relationships to spread these tools and practices throughout healthcare systems for broad uptake. The third is to activate patients and families in organizational design and governance to drive system-level change. The action team's vision, goal, and strategies are depicted in Figure 2 below.

Figure 2. Patient and Family Engagement Action Pathway



Tools for Dialogue

For patient and family preferences to drive healthcare delivery and achieve the goals of the Partnership for Patients, patients, families and their caregivers must have effective tools that allow them to articulate their needs, goals, and values. In response to this need, the action team is promoting the domains of a "*Patient Passport*," a tool to assist patients in having meaningful and effective communication with providers at the point of care, particularly in the hospital setting. The *Patient Passport* is modeled on existing tools, such as "*My Healthcare Passport*" that the NHS system uses in the United Kingdom to help individuals with learning disabilities express their needs and preferences when in hospital. Another model is the "*Patient Passport"* developed in partnership at the Mattel Children's Hospital UCLA between the parents of medically complex children and emergency physicians to expedite triage. Exemplars of these tools are presented in Figure 3 below.

Figure 3. Exemplars of Existing Patient Passports

PATIENT PASSPORT

Mattel Children's Hospital UCLA

NAME: ____________ **UCLA MRN:** ____________ **DOB:** ________

PRIMARY SERVICE (ATTENDING): ____________

OTHER INVOLVED SERVICES: ____________

DIAGNOSIS: ____________

PROBLEM LIST: ____________

DRUG ALLERGIES: ____________

OTHER SENSITIVITIES/CONSIDERATIONS: ____________

******ATTENTION TRIAGE NURSE!******

This patient is medically fragile. If here for an acute illness, this patient should be assessed immediately upon arrival.

******ATTENTION ED PHYSICIANS & STAFF******

☐ **IF CHECKED, THIS PATIENT IS IMMUNOCOMPROMISED AND SHOULD NOT BE PLACED NEAR ANY POSSIBLY CONTAGIOUS PATIENTS OR IN HALLWAYS**

- **STRONG RECOMMENDATIONS TO BE STARTED WHILE CONTACTING PEDIATRIC SERVICE (FOR IVF, ANTIBIOTICS, INITIAL LABS, FREQUENCY OF VITAL SIGN MONITORING):** ____________
- **VITALS:** Monitor more frequent if ill: ☐ Q4 ☐ Q2 ☐ Q1 ☐ Continuous
- **UCLA RRMC ED PLEASE PAGE PEDIATRIC HOSPITALIST (90054) OR PEDIATRIC ____________ SERVICE UPON ARRIVAL TO TRIAGE. If outside RRMC call Hospital Operator 310-825-9111 and ask to page the pediatric specialty service.**

PRIMARY ATTENDING MD NAME ____________ **DATE** ________

PRIMARY ATTENDING MD SIGNATURE ____________

Rather than focusing on a particular demographic, the *Patient Passport* domains target the general population, although they could be modified for specific patient needs. The action team has agreed that the following domains are critical:

- Patient Identification—name, preferred language
- Critical Health Information—allergies, medications, disability, relevant care plans, primary contact, caregiver information, etc.
- Health Team—PCP, specialists, care team members
- Health History and Goals—significant health events, hospitalizations, coping with my health conditions, good days/bad days, health goals for when I get out of the hospital
- What I Need While I'm Here—major concerns, what makes me comfortable, what I need help with, etc.
- Personalized Photo—how I look and what I do when I'm not sick
- Discharge—what to do when I get home
- Advance Care Directives and End of Life Preferences—how I want my care to be handled

This tool is unique because it allows the patient to initiate and guide patient-provider conversations, as opposed to other tools that attempt to guide patients through the health system or tell them what to do, what to ask, and what to expect. It is written by the patient in the patient's voice, and is intended as a complement to other resources. Both its content and style are intended to make frontline staff's work simpler and more effective by presenting critical information about the patient in a concise and meaningful way. Also, small things—like a personalized photo—help to humanize the experience of the patient/provider encounter. The value of the passport is that it can be developed in partnership with patient advocates, frontline staff, and health administrators to be responsive to each of these unique perspectives.

Partnership

The action team is utilizing its networks and relationships to spread the *Patient Passport* domains in a number of settings. Griffin Hospital—a Planetree-designated facility—in Connecticut is integrating the domains into a community-wide "Patient-Family Activation Initiative," with goals of increasing the delivery of healthcare that honors patient preferences; developing shared decision-making partnerships between patients and their healthcare providers; improving population health; and increasing engagement and activation of patients and families. Specific training modules for healthcare providers, Patient and Family Partner Council members, and community stakeholders will focus on initiating conversations and sharing tools and resources.

Interest in the domains of the *Patient Passport* has been expressed by a number of health plans, a national pharmacy chain, a patient safety technology company, and several Patient and Family Advisory Councils (PFAC) of health systems. The action team continues to promote partnerships that will spread the passport concept as a means of authentically engaging patients, and as a potential system-level initiative for consideration by PFACs and hospital boards.

Activating Patients to Drive Organizational and System-Level Change

The final strategy involves the activation and engagement of patients and families to be the drivers of the change they want to see. Changing organizational culture to be patient-and family-centered requires the engagement of healthcare leadership, but not every system or organization has the necessary leadership to shift an established provider-centric culture. One of the most promising ways to influence organizational culture is through patients. By providing patients with a ready-made tool like a *Patient Passport*, they can be more empowered to initiate conversations with their healthcare team(s) about their needs, goals, and preferences.

In addition to spreading the domains of the passport, the PFE Action Team is considering key messages to spread awareness about the passport concept, as well as guiding principles for successful development and implementation, such as the importance of patient ownership, engagement of frontline staff, and consistent messaging about the purpose of a passport so that hospitals have necessary context. Ideally a *Patient Passport* would be "agile" and work well in multiple units; frontline staff would be prepared to read the passport; and PFACs would find value in initiating such a project to meet its patient and family engagement goals.

The Path Forward— Action Team Members as Change Agents

The action team is actively collaborating with stakeholder groups in the public and private sectors to achieve the goals of the Partnership for Patients, and is working with the National Content Developer, consumer advocates, and the NQF membership to spread promising practices and resources. The action team is holding monthly calls, in-person meetings, and two open forums to engage a broad array of stakeholders in dialogue. These activities are organized to foster the identification of opportunities to augment, amplify, and accelerate the strategies as well as other patient- and family focused efforts in the field. Team members are providing updates on actions related to progress on the pathway, and identifying the opportunities and activities that will spread best practices and programs, particularly the *Patient Passport*. Updates on the activities and accomplishments of the action team members are highlighted in NQF's Quarterly Impact Reports, and through in-person meeting and webinar summaries posted to the NQF website. The final Quarterly Impact Report (due October 15, 2014) will include a summary of the action team's activities and results over the course of the project.

As demonstrated by the momentum generated by the PFE Action Team, the subject of person-centered care is one that is very personal and can motivate positive change in the healthcare system. Action team members have expressed a strong desire to continue this work beyond the scope of the deliverable through the specific strategies identified in the pathway. Several members are exploring partnership opportunities to test and pilot the model independently. Others are focusing on activating patients through educational materials and social media.

Endnotes

[1] Safety is Personal: Partnering with Patients and Families for the Safest Care. National Patient Safety Foundation. Boston, 2014.

[2] Kristin L. Carman et al, Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. *Health Affairs*. 32 (2):223-231; 2013.

[3] Crossing the Quality Chasm: A New Health System for the 21st Century. Institute of Medicine. National Academy of Sciences. Washington DC. 2000.

[4] Angelica Theirot, 1978