



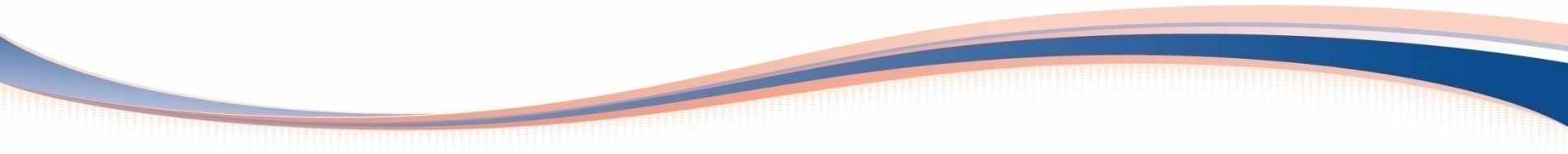
Patient and Family Engagement

Part I. Making the Case

- ILQPC & PQCNC slidesets: Engaging patients and families in QI work - What it is, why it matters, how to get started
- Evidence from PQCNC: Bringing Depth and Meaning to Perinatal Quality Improvement by Partnering With Patients
- Tools for hospitals to make the case to stakeholders: ILPQC Patient & Family Engagement, ILPQC Partnering With Patient & Family Advisors
- Additional resources not in this toolkit: Council on Patient Safety in Women's Health Care: 'Voices of Impact' video series

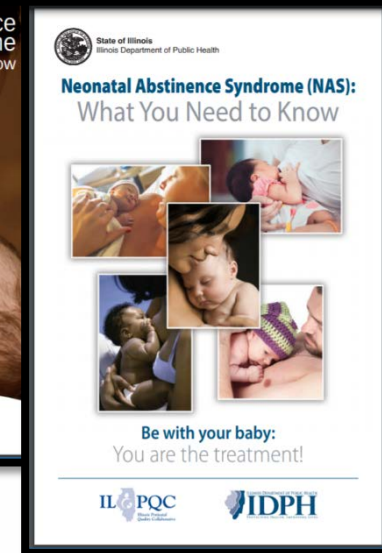
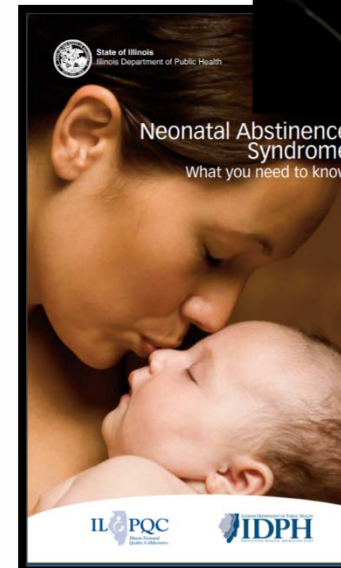


Making the Case: Improving Outcomes Through Patient Engagement



Patient / family advisors at the collaborative level

- 6 patient family advisors
- Provide input on initiative development
- Share stories at ILPQC events
- Improve patient / provider education materials
- Identify strategies to support hospital teams to engage patients/families in their QI work



Supporting hospital efforts: Where we've been



- Awareness and education for hospital teams and administration
- Tools to help hospital teams engage patients/families in QI work
- ILPQC Central facilitating patient/family advisor matches with hospital teams

Why it matters

“Embedded at every level of the organization and in all stages of clinical initiatives, patients and family members have been strong catalysts for change in PQCNC’s neonatal and maternal initiatives.”

- Perinatal Quality Collaborative of North Carolina (PQCNC)

- PQCNC Obstetric Hemorrhage (OBH) Story
 - Worked with OBH survivors to identify 5 essential practice areas and co-design relevant resources for hospital teams
 - PQCNC assisted hospital teams to contact recent OBH survivors following discharge to ask for feedback on their patient and family support experience
 - Feedback highlighted missed opportunities to partner with patients, including delayed, absent, or unclear information sharing - especially around the assessment of patient risk

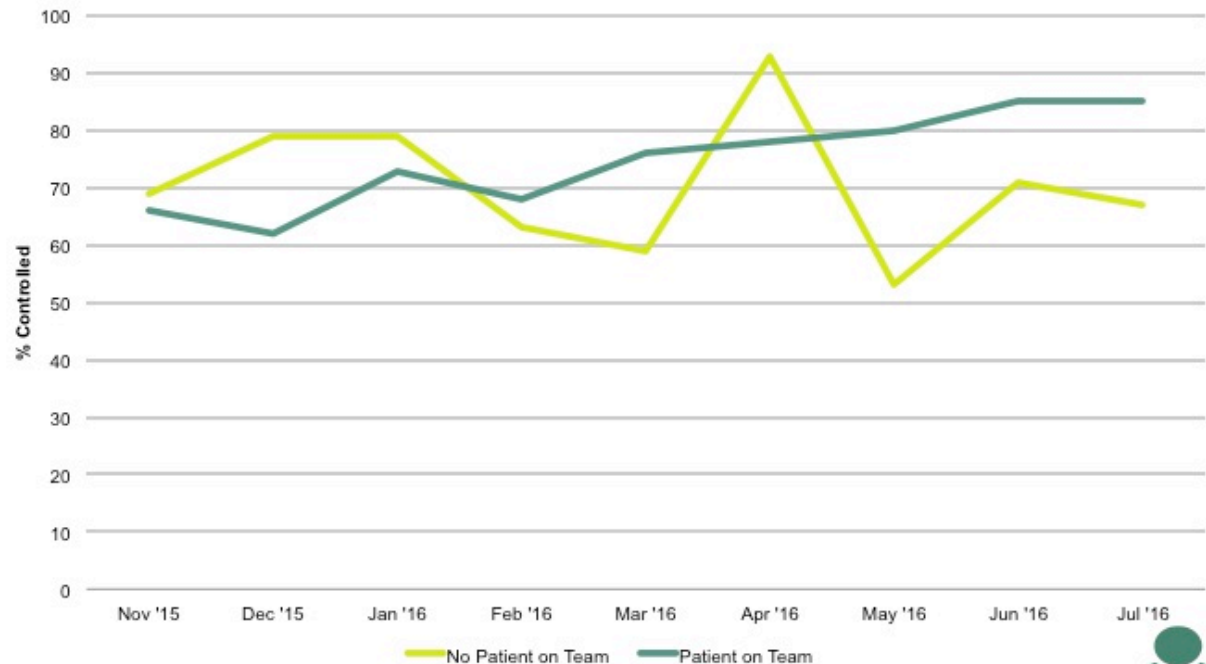
Rouse, DeJoseph, & Ollendorff, 2019, Clinical OBGYN, 62(3), 528-38.

Improved outcomes



Engaging patients in your QI efforts improves your outcomes!

Percentage of Patients with SBP >160 or DBP >110 Controlled within One Hour



From T.B. Rouse, 2017, presentation given to ILPQC HTN teams.

Supporting hospital efforts: Where we're going



- Collaborative goal: Every hospital QI team has a patient / family advisor participating in some capacity to advance ILPQC's goal of improving outcomes for moms and babies
- Patient / family advisors to hospital QI teams can:
 - Share a personal story
 - Provide feedback on materials
 - Attend provider meeting or grand rounds
 - Attend QI meetings

The Patient and Family Voice: Engaging Patients and Families for Improved Quality and Safety

Adapted from Tara Bristol

January 26, 2015



Defining Patient- and Family-Centered Care

*“An approach to the planning, delivery, and evaluation of health care that is grounded in **mutually beneficial partnerships** among health care providers, patients, and families.”*

Source: Institute for Patient and Family Centered Care



Nothing About Patients, Without Patients

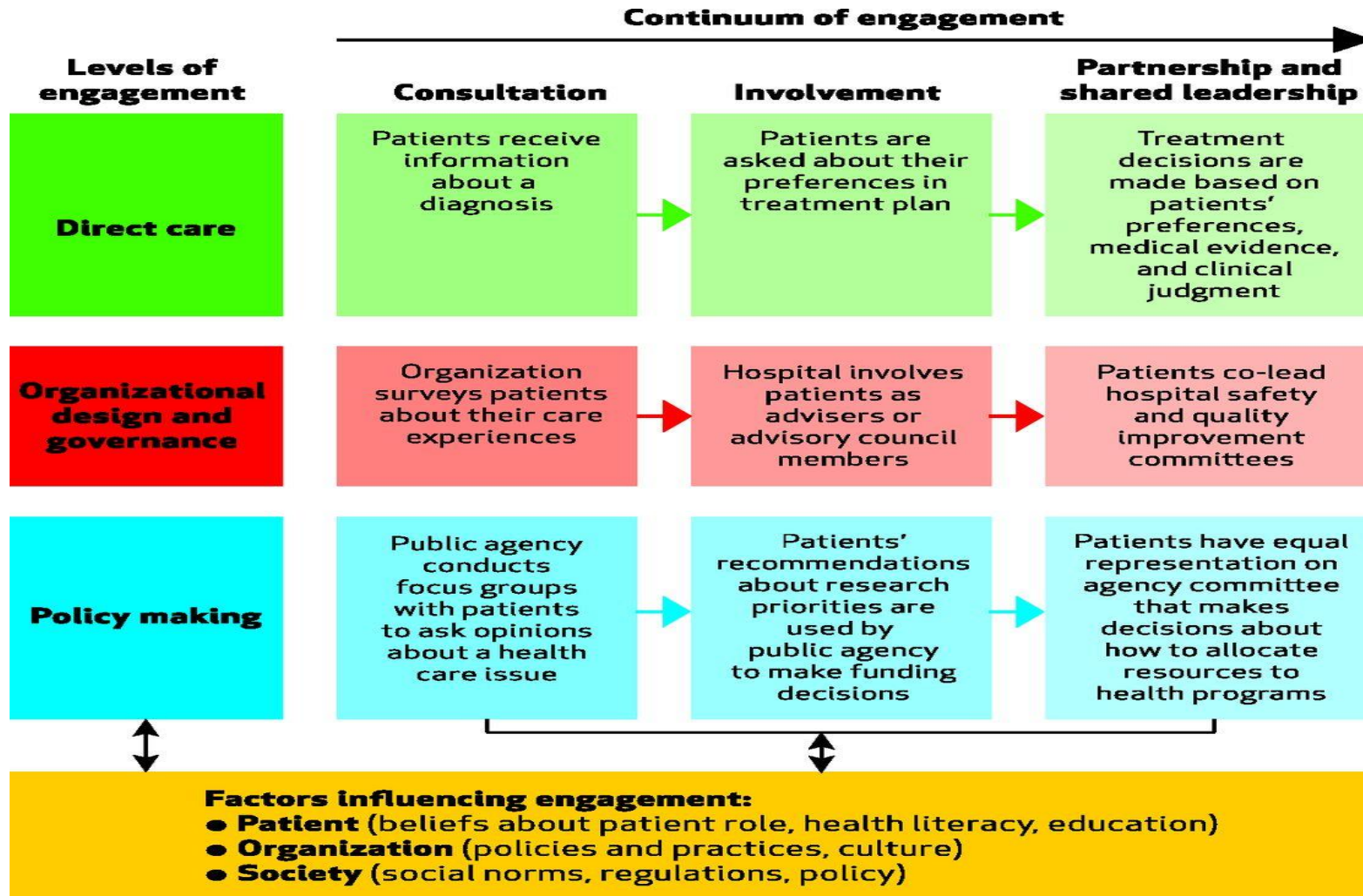


The question is not “if” or “when,” but “how” ...

- Patient & Family Engagement is a ***foundational priority***.
- Leading organizations are ***investing*** time, money and people in this body of work. ***Leaders*** include:
 - ✓ IPFCC: Institute for Patient & Family Centered Care
 - ✓ AHRQ: Agency for Healthcare Research Quality
 - ✓ IHI: Institute for Healthcare Improvement
 - ✓ AHA: American Hospital Association
 - ✓ NQF: National Quality Forum
 - ✓ TJC: The Joint Commission
 - ✓ The Beryl Institute



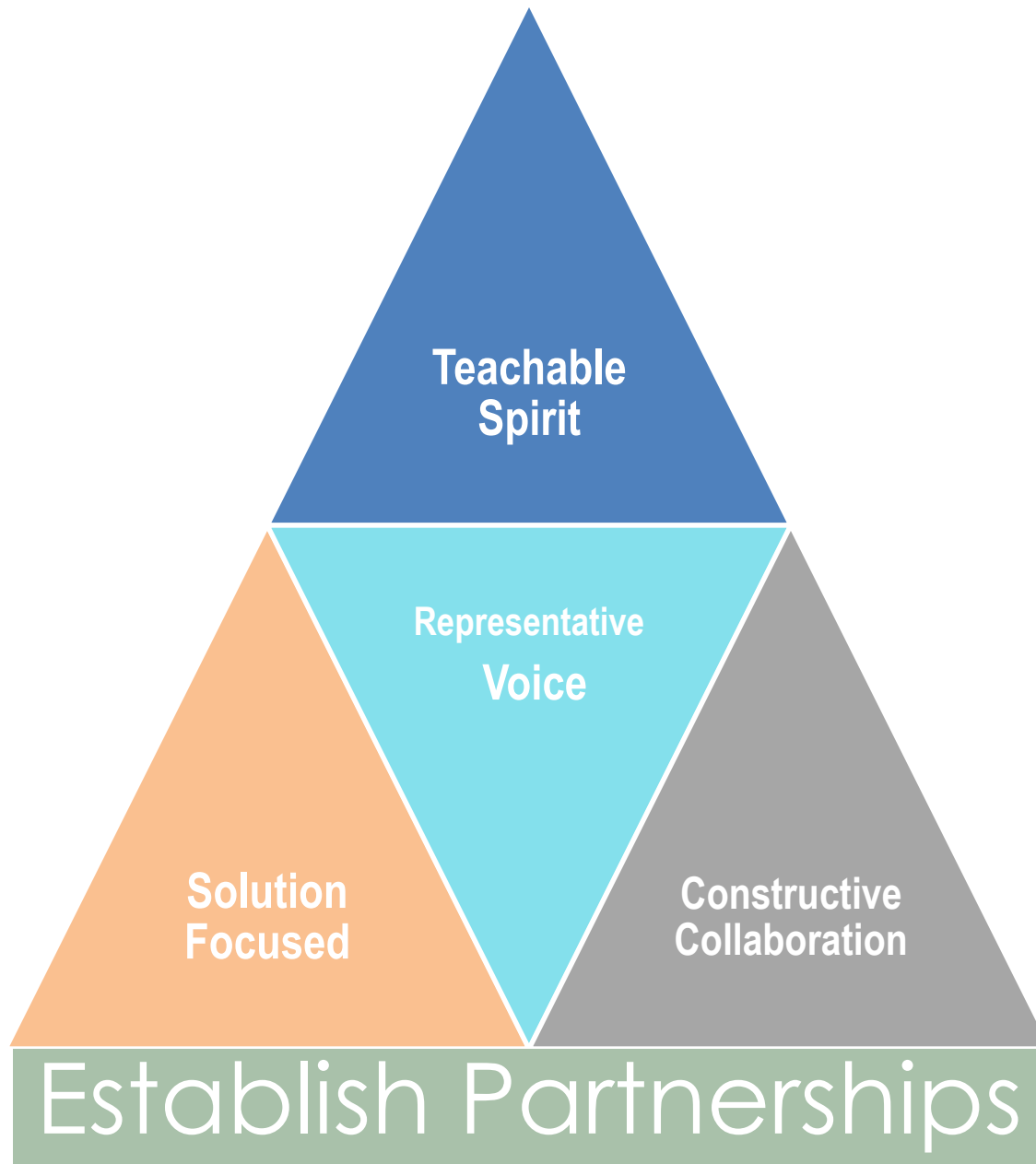
A Framework for Patient and Family Engagement in Health and Health Care



“Having a patient & family representative in the room changes the conversation in every way.”

-Jim Conway





The Role of Patients and Families...

Patient & Family Advisors work in a variety of healthcare settings sharing their personal stories to **represent** all patients & families in providing an educated perspective of care by bringing **authenticity**, empowerment, respect and **inspiration** to the design and delivery of healthcare systems. Patient & Family Advisor roles include partner, educator, speaker, listener, advocate, **collaborator** and leader, ensuring the focus of healthcare is centered on the patient & the family.*

*Collaboratively written by the patient & family advisors in attendance at the IHI Forum, 2012



“Patient engagement is a skill, not a trait.”

Institute of Medicine (IOM) 2013 Report, *Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement*

Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement

In February 2013, the Institute of Medicine's Roundtable on Value & Science-Driven Health Care convened a workshop, gathering patients and experts in areas such as decision science, evidence generation, communication strategies, and health economics to consider the central roles for patients in bringing about progress in all aspects of the U.S. health care system. This Meeting Summary is being released in conjunction with a complete transcript of the event, the Workshop Proceedings. Over the course of 2 days, 31 speakers commented on the importance of patient and caregiver engagement in achieving the best care at lower cost.

The discussions highlighted the critical role and capacity for patients and families to be leaders in informed care decisions, knowledge generation, and value improvement.

Individual workshop participants identified a few overarching themes and messages.

Overarching themes and messages:

- **Culture dominates.** “Culture eats strategy for lunch every time,” as mom-turned-advocate Cristin Lind noted. Thus, improving the quality of the care experience and using limited resources wisely will require significant culture shifts.
- **“Listen first, listen fully.”** That’s what Ekene Obi-Okoye, a premedical intern at the University of California, San Francisco, learned as she supported patients with breast cancer. By listening first and listening fully, patient and caregiver voices are integrated fully into every possible level of decision making—care, system design, and policy making—and the quality of care improves.
- **Patient engagement is a skill, not a trait.** Being an engaged patient and actively engaging patients are not intuitive skills. Patients and clinicians learn these skills over time and through partnership with a supportive care team.
- **Trust matters.** Effectively delivering cost and quality information requires trusted translators who convey information in ways that are easy to understand.
- **Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs, and better health.** Achieving and exceeding these three basic aims of health and health care policy calls for partnering with patients as leaders and drivers of care improvement.

INFORMED, SHARED CARE DECISIONS

A meaningful care experience is when the patient is fully informed and the provider has elicited the patient's preferences and goals.

Evidence strongly indicates that when patients are fully informed and engaged in making decisions about their care, patient satisfaction goes up, results improve, and health care costs go down, stated Gary Langer of Langer Research Associates and a number of other workshop participants. In pursuit of more and higher-quality shared decision making, the first workshop session explored how to increase demand for shared decisions, as well as the changes in infrastructure, culture, and training that would be necessary.



PQCNC Patient and Family Engagement (PFE) Initiative

Mission:

Create a multidisciplinary, hospital-based community that is focused on providing a standardized approach to, and building of support for, the recruitment, training, and engagement of patients and families with diverse perspectives as meaningful members of quality improvement teams.



**Perinatal Quality Collaborative
of
North Carolina**

**Patient and Family Engagement
Action Plan**

Overall Aim:

Create a multidisciplinary, hospital-based community that is focused on providing a standardized approach to the recruitment, training, and employment of patients and families as partners in perinatal improvement efforts by January 2014.

Outcomes

Change Ideas

Each facility will have a process in place for identifying patients/family members to assist with the improvement team(s) they have chosen to focus on

- Identify a person(s) who will solicit and document patient/family member referrals
- Determine characteristics and perspective/experience desired in potential patient/family partners (e.g., time since discharge, diversity) and provider/staff champions (e.g., utilize a checklist for attitudes)
- Identify sources to approach for referrals (e.g., bedside nurses, social workers, patient relations)
- Create educational tools to share with providers/staff regarding what makes an effective patient/family partner
- Educate providers/staff regarding the referral process

Each facility will contact 3 patients/family members about assisting with their improvement efforts

- Determine if other departments/teams should be engaged before contacting patients/family members (e.g., Patient Experience Team, Volunteer Services)
- Identify a lead person(s) to interview and document contact with potential patient/family partners
- Determine roles for patients/families (i.e., what are we asking them to do)
- Create interview/application tools to be used with every potential candidate (e.g., interview scripts, application, acceptance/rejection letters)
- Determine readiness criteria for use in selecting potential candidates

Each facility will have 1 patient/family member join and attend each meeting for the improvement team(s) they have chosen to focus on

- Determine facility-level requirements for patients/family members (e.g., volunteer training, background checks)
- Create orientation tools for use in onboarding patients/family members (e.g., information about the unit and providers, goals of partnership, expectations regarding participation, meeting etiquette)
- Identify a person(s) to track patient/family member progress towards completing training requirements and orientation
- Identify a person(s) on the improvement team to be the point of contact for patients/family members, to track patient/family member attendance, and orient the team
- Orient improvement team members regarding the role of patients/family members on the team

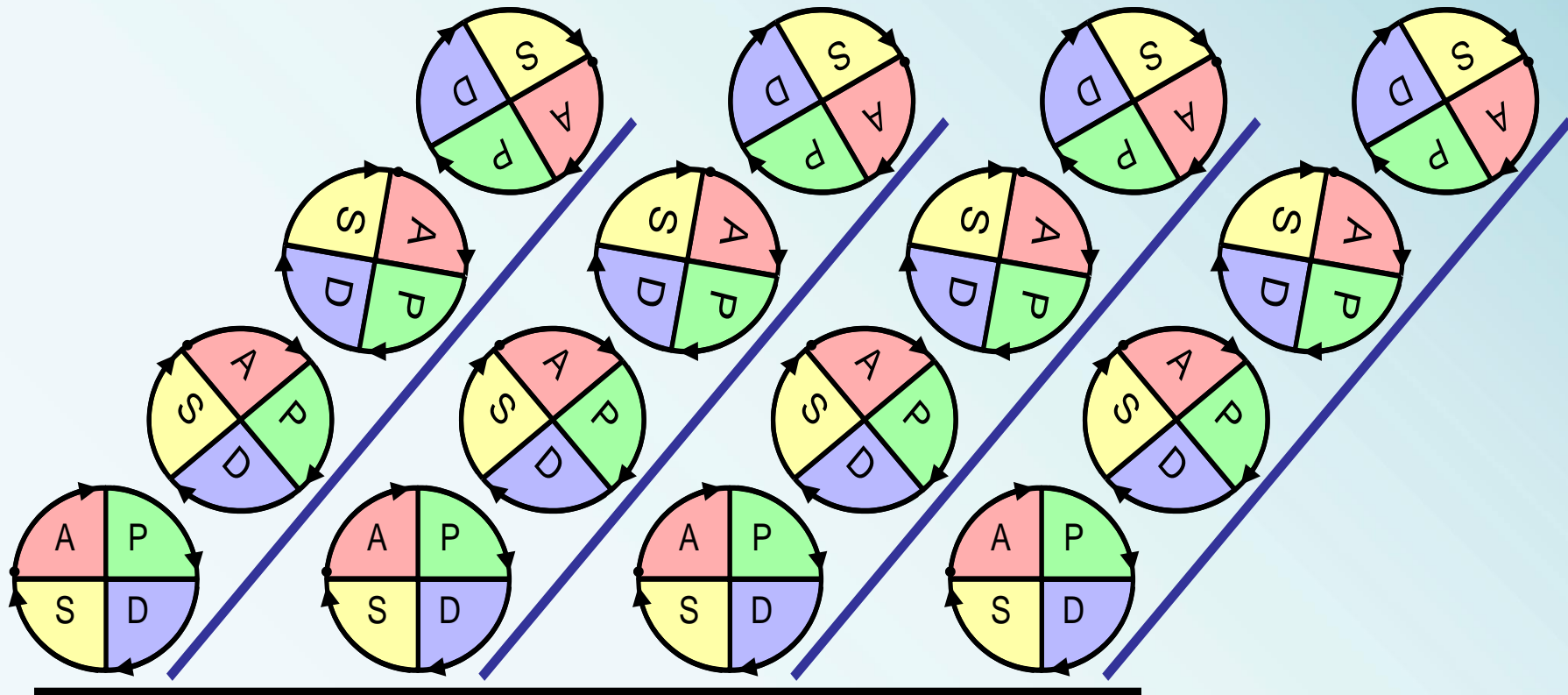
Each facility will have a process in place for educating providers/staff regarding the importance of the patient/family perspective

- Identify potential forums (new or existing) for educating providers/ staff (e.g., new nurse residency, staff meetings, lunch and learns, online modules)
- Develop curriculum for educating providers/staff
- Identify a lead person(s) to facilitate and track educational opportunities
- Identify patients/family members who are able to assist with education
- Create tools for tracking the number and type of providers participating in education and a system for evaluating the effectiveness of the opportunity



**PFE
Action Plan**

Working in Parallel on Multiple Change Concepts (Aim: Engage Patients & Families)



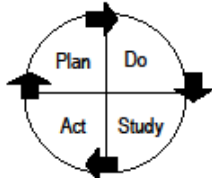
**Identify
Patient/
Family
Advisors**

**Contact
potential
advisors**

**Include
patients
on teams**

**Educate and
improve provider
skills and
knowledge**

What have you been working on this month?



PDSA WORKSHEET

Team Name:	Date of test:	Test Completion Date:
Overall team/project aim:		
What is the objective of the test?		
What 90 day goal does the change impact?		



PLAN:

Briefly describe the test:

How will you know that the change is an improvement?

What driver does the change impact?

What do you predict will happen?

PLAN

List the tasks necessary to complete this test (what)	Person responsible (who)	When	Where
1.			
2.			
3.			
4.			
5.			
6.			

Plan for collection of data:

DO: Test the changes.

Was the cycle carried out as planned? Yes No

Record data and observations.

What did you observe that was not part of our plan?

STUDY:

Did the results match your predictions? Yes No

Compare the result of your test to your previous performance:

What did you learn?

ACT: Decide to Adopt, Adapt, or Abandon.

- Adapt:** Improve the change and continue testing plan. Plans/changes for next test:
- Adopt:** Select changes to implement on a larger scale and develop an implementation plan and plan for sustainability
- Abandon:** Discard this change idea and try a different one



**Patient and Family Engagement Initiative
Monthly Data Collection Form**

1. Do you have a process in place for identifying patients / family members to assist with the work of your improvement team? (circle one) Yes No
2. How many patients / family members have you identified in the past month? (total #) _____
3. Of those identified, how many have you contacted? (total #) _____
4. Of those contacted, how many were approached prior to patient discharge? (total #) _____
5. Of those contacted, how many were approached following patient discharge? (total #) _____
6. Of those contacted, how many have agreed to assist? (total #) _____
7. How many improvement team meetings have been held in the past month? (total #) _____
8. How many patients /family members attended the improvement team meeting(s)? (total #) _____
9. Do you have a process in place for educating providers/staff regarding the importance of the patient/family perspective? (circle one) Yes No
10. Which modes of education have been used in the past month? (check all that apply)
 - ____ In-person training/single discipline of providers/staff
 - ____ In-person training/multi-disciplinary
 - ____ Web-based training/single discipline of providers/staff
 - ____ Web-based training/multi-disciplinary
 - ____ Provision of written materials/single discipline of providers/staff
 - ____ Provision of written materials/multi-disciplinary
11. How many providers/staff have received education in the past month? (total #) _____
12. How many patients/family members have assisted with provider/staff education? (total #) _____
13. How many patients / family members have attended PQCNC webinars this month? (total #) _____



PQCNC PFE

By the numbers...

15

Hospitals

8

Months

Contacted **166**
Patients and Family
Members

Percentage of Patients and Families Members who
Agreed to Assist

55%

220 Volunteer Hours from
Patients and Family Members

Over **1200**
Providers Educated

