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

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

Factors influencing engagement:
- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)

Carman K L et al. Health Aff 2013;32:223-231
“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*
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

<table>
<thead>
<tr>
<th>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</th>
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<tbody>
<tr>
<td>Each facility will contact 3 patients/family members about assisting with their improvement efforts</td>
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<tr>
<td>Each facility will have 1 patient/family member join and attend each meeting for the improvement team(s) they have chosen to focus on</td>
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<tr>
<td>Each facility will have a process in place for educating providers/staff regarding the importance of the patient/family perspective</td>
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Change Ideas

- 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

- 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

- 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

- 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
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?

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<tr>
<th>PLAN</th>
<th>DO</th>
<th>STUDY</th>
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<tr>
<td>Briefly describe the test:</td>
<td>Test the changes.</td>
<td>Did the results match your predictions?</td>
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<td>How will you know that the change is an improvement?</td>
<td>Was the cycle carried out as planned?</td>
<td>Yes □ No □</td>
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<td>What driver does the change impact?</td>
<td>Record data and observations.</td>
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<td>What do you predict will happen?</td>
<td>What did you observe that was not part of our plan?</td>
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<thead>
<tr>
<th>PLAN</th>
<th>Person responsible (who)</th>
<th>When</th>
<th>Where</th>
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Plan for collection of data:

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<th>ACT</th>
<th>Adopt: Improve the change and continue testing plan. Plans/changes for next test:</th>
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<tr>
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<td>Adopt: Select changes to implement on a larger scale and develop an implementation plan and plan for sustainability</td>
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<td></td>
<td>Abandon: Discard this change idea and try a different one</td>
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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 PGCNC 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