

# Engaging Families in Quality Improvement

Illinois Perinatal Quality Collaborative  
Annual Conference

November 10, 2014

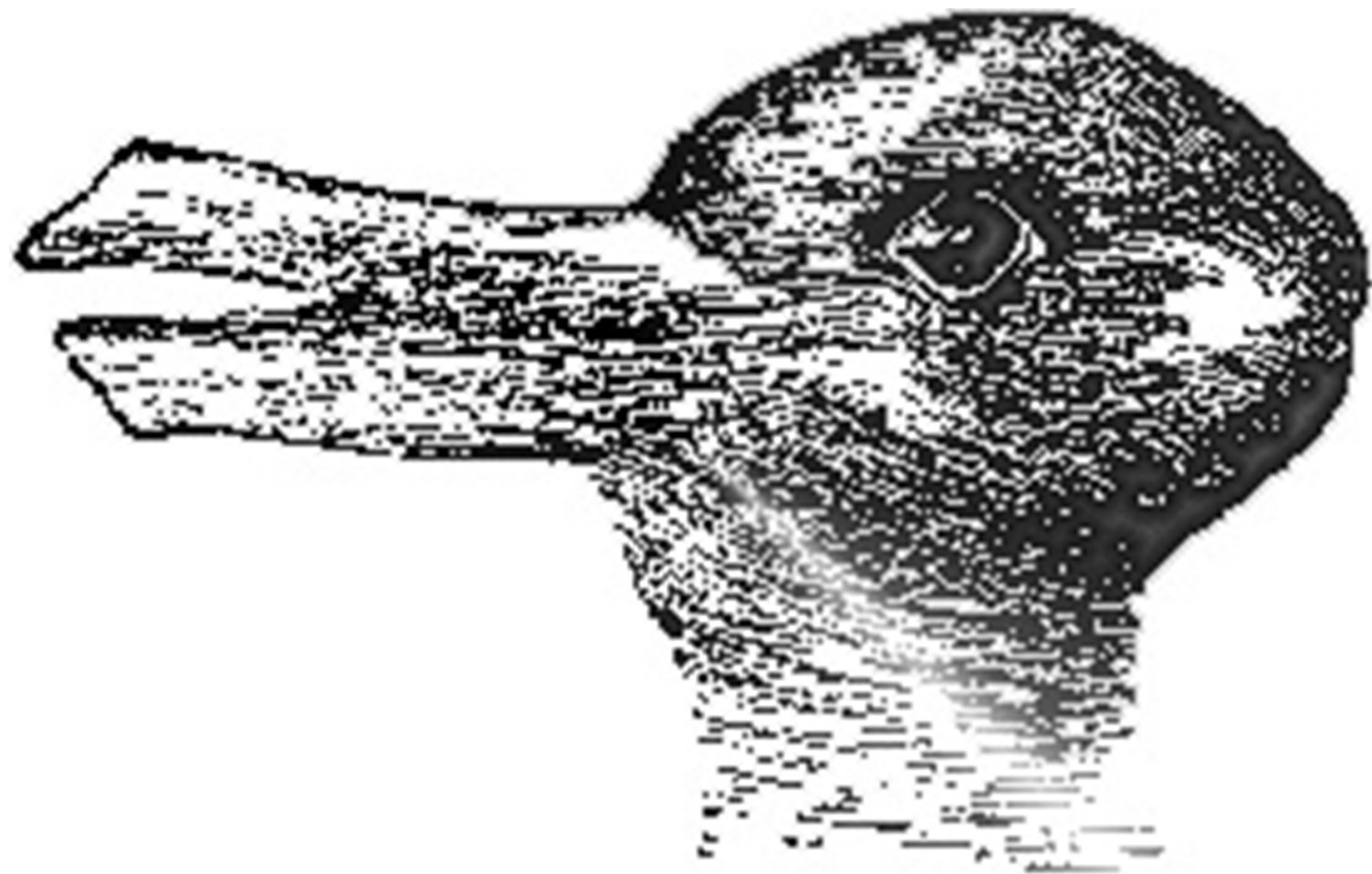
**Tara Bristol**

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Perinatal Quality Collaborative of North Carolina (PQCNC)

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# Definitions and Landscape



# 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 me without me”
- No longer doing things “to” or “for,” but doing things “with”
- What would I want done for myself?  
My family members?

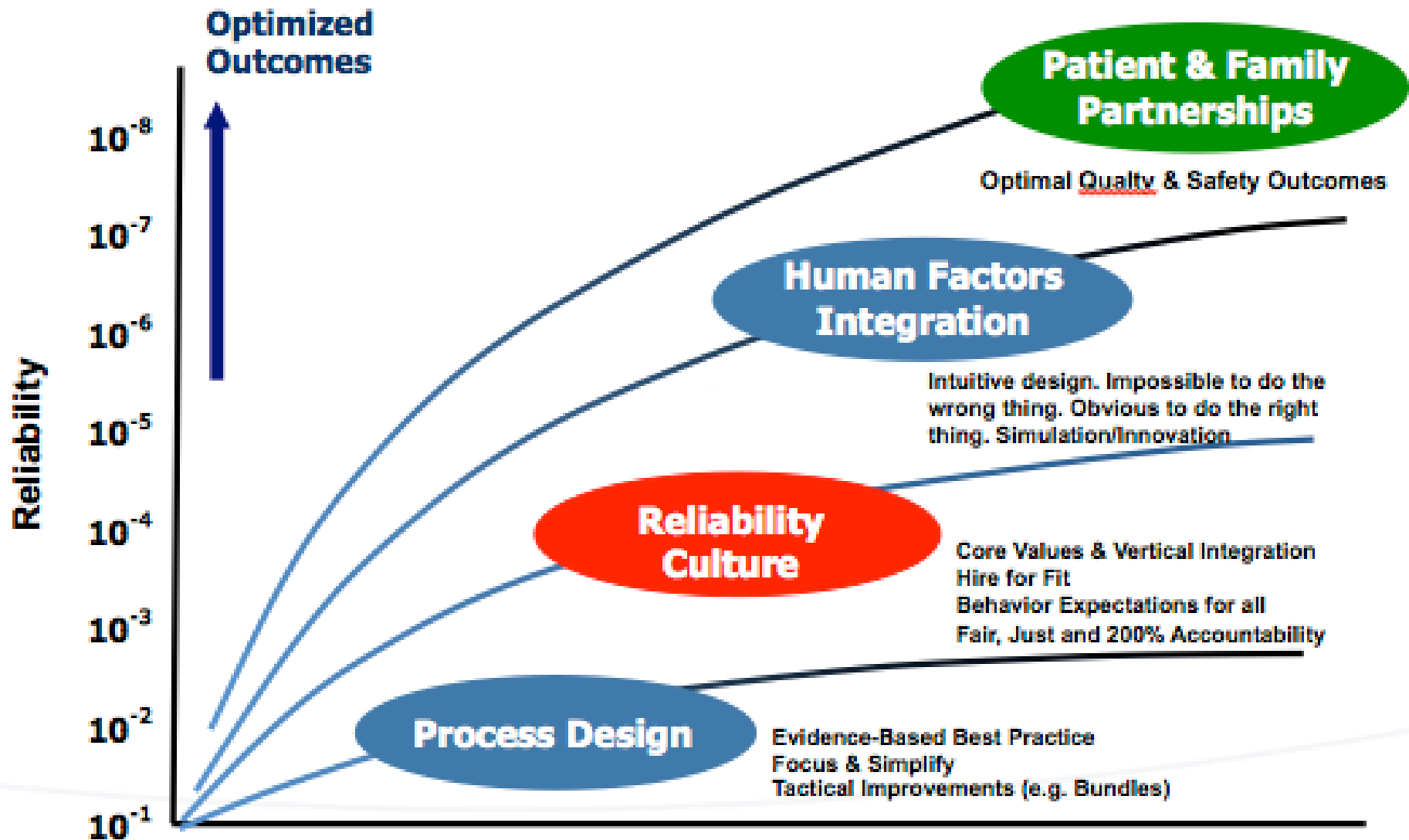


# The question is not “if” or “when,” but “how”...

- 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
  - ✓ TJC: The Joint Commission
  - ✓ The Beryl Institute



# The Road to MSH Success



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# Framework for Engagement



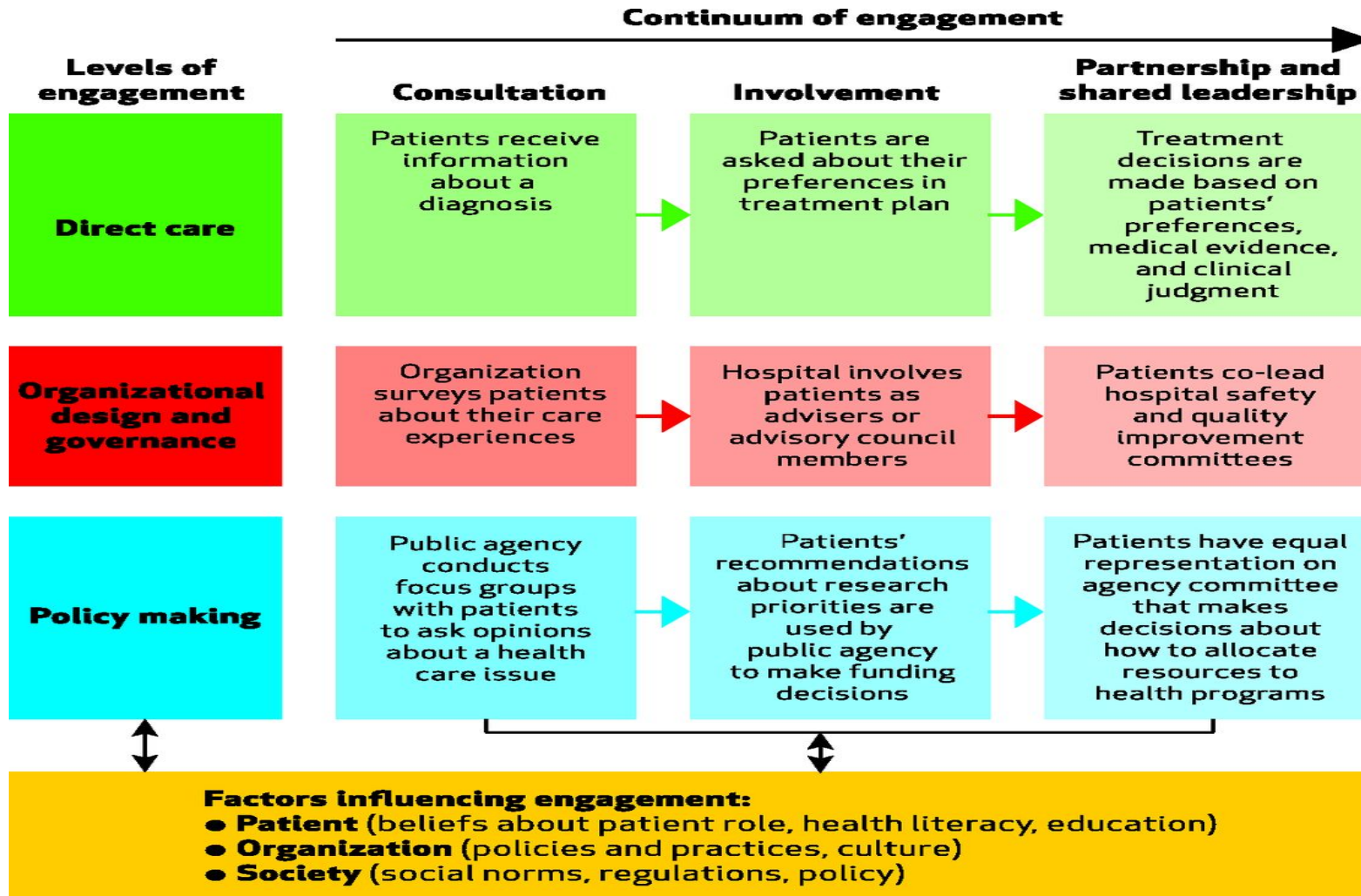
# Framework for Engaging Health Care Users



Source: AHA COR, 2013.



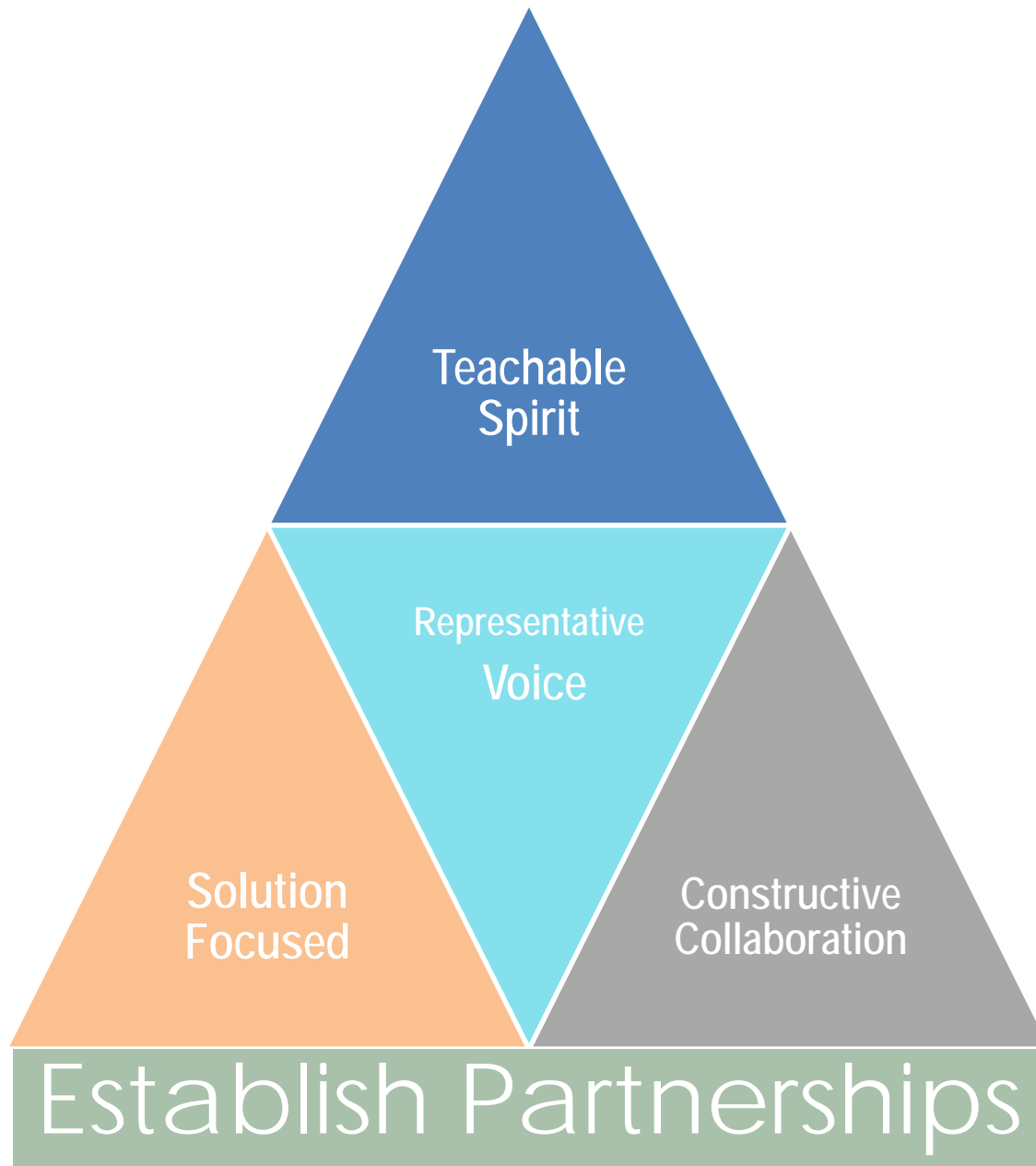
# A Framework for Patient and Family Engagement in Health and Health Care



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

-Jim Conway





# HOW STORYTELLING AFFECTS THE BRAIN

## NEURAL COUPLING

A story activates parts in the brain that allows the listener to turn the story in to their own ideas and experience thanks to a process called neural coupling.

## MIRRORING

Listeners will not only experience the similar brain activity to each other, but also to the speaker.



## DOPAMINE

The brain releases dopamine into the system when it experiences an emotionally-charged event, making it easier to remember and with greater accuracy.

## CORTEX ACTIVITY

When processing facts, two areas of the brain are activated (Broca's and Wernicke's area). A well-told story can engage many additional areas, including the motor cortex, sensory cortex and frontal cortex.

<http://www.xtrii.com/thought-leadership/how-storytelling-affects-the-brain>



# Patient and Family Engagement – Opportunities and Challenges



# 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





“Collaboration means that no one interest group is always right. It means taking what you think and what I think, and what someone else thinks, and coming up with something that works for everyone.”


-B. Crider

From: *Essential Allies,  
Families as Advisors*



# “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*

MEETING SUMMARY  AUGUST 2013

INSTITUTE OF MEDICINE  
OF THE NATIONAL ACADEMIES  
Advising the nation • Improving health

For more information, visit [iom.edu/partneringwithpatients](http://iom.edu/partneringwithpatients)

## 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.*

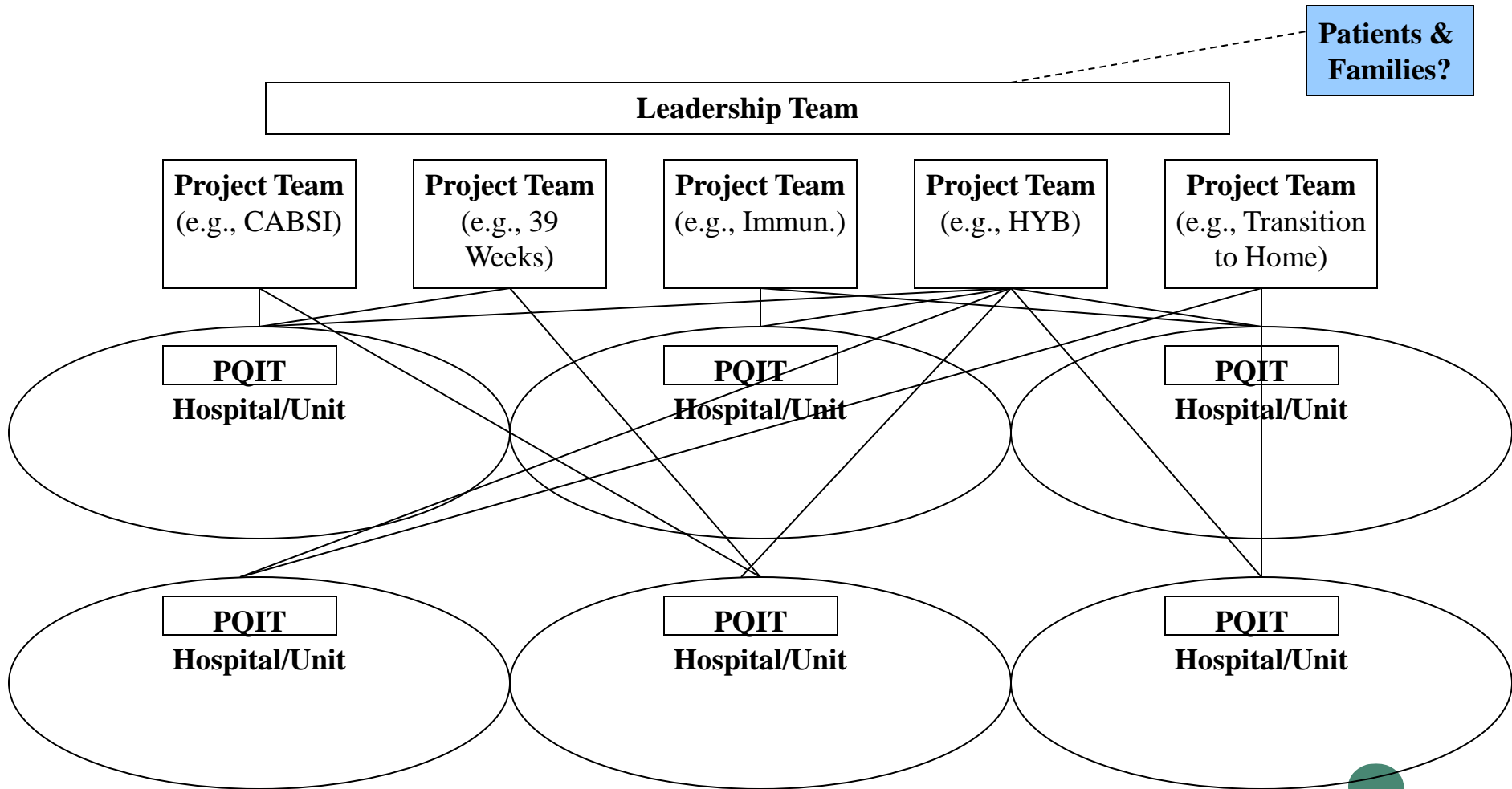
Evidence strongly indicates that when patients are fully informed and engaged in making decisions about their care, patient satisfaction goes up, results improve, and health care costs go down, stated Gary Langer of Langer Research Associates and a number of other workshop participants. In pursuit of 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.



# Patient and Family Engagement – A Journey, Not a Destination



# Where Do We Put Patients and Families?



# Patients and Families in PQCNC

**Leadership Team**

**Project Team**  
(e.g., ROP)

**Project Team**  
(e.g., CPAP)

**Project Team**  
(e.g., Immun.)

**Project Team**  
(e.g., HYB)

**Project Team**  
(e.g., Transition to Home)

**PQIT**  
**Hospital/Unit**  
Including Patients &  
Family Members

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## "Gabby"

On the importance of the Catheter Associated Blood Stream Infections (CABS) initiative...



<http://www.pqcnc.org/?q=node/12879>

### Materials

- ↳ About PQCNC
  - ↳ Institutions
- ↳ Members
  - ↳ Conferences
- ↳ Initiatives
- ↳ Resources
- ↳ Family Focus Group
- ↳ Of Interest
- ↳ Blogs
- ↳ Friends of PQCNC

### Members





“... ask the nurse or doctor; ‘Did you remember to wash your hands?’ ...”



*From the Duke RAIN Family Letter*





“...I want to highlight the role of the family member...”



Upcoming important dates, next steps for the Milk Initiative Well Baby Track...

(This email goes out to the key contact person from each team in the collaborative. Please share relevant information with your team members or others at your hospital.)

October 27, 2010

## Measures in the service of your improvement goals



In this email I want to highlight the role of the family member, preferably a mom who has experienced your services. Someone who has experienced the services and looks at our results and our work processes with us can provide valuable insight, perspective, and that 'aha!' light-bulb moment. That viewpoint can inform both the goals and the messages we use as we strive to support every mother to feed her baby. Input from fathers and other key persons in the mother's journey can also shape the work in positive ways.

Tara Bristol has provided a [sample invitation letter](#) and [sample welcome letter](#) for family members for you to personalize and use if you choose. [Contact her here.](#)



[Home](#)[Calendar](#)[Contact Us](#)[Oldnet](#)[Login](#)[Got an Idea?](#)[PAL](#)

## PQCNC Conference on Patient and Family Centered Perinatal Care

Held Tuesday, May 18, 2010, 10:00 AM - 3:00 PM, the **PQCNC Conference on Patient and Family Centered Perinatal Care** explored the relationship between patient- and family-centered care, quality and safety....

Featured Speaker:



**William E. Schwab, M.D.** is the **Secretary of the Board of Directors for the Institute for Family-Centered Care**. He is a professor at the University of Wisconsin, Department of Family Medicine and Director of its Madison Family Practice Residency Program. He is formerly Director of Clinical Operations for the department. Bill is a recipient of the Baldwin E. Lloyd, M.D., Clinical Teacher of the Year Award from the University of Wisconsin Department of Family Medicine and Educator of the Year from the Wisconsin Academy of Family Physicians. A nationally recognized leader in medical education about the care of children and adults with chronic illness and disabilities, Bill is a frequent speaker and consultant to hospitals, medical schools, and community agencies around the country. Bill's perspective is augmented by his experience as the parent of a child with complex medical needs.

### Materials

- [About PQCNC](#)
  - [Institutions](#)
- [Members](#)
  - [Conferences](#)
    - [Patient / Family Centered Perinatal Care](#)
      - [39 Weeks 1/26/2010](#)
      - [39 Weeks 4/27/2010](#)
    - [PQCNC III](#)
    - [NICU Family Educators](#)
    - [PQCNC V](#)
- [Initiatives](#)
- [Resources](#)
- [Family Focus Group](#)





# Changing Culture

“We are professionals with a license to practice. We don't need families to let us know if we do it wrong.”





*Hope is not a plan.*  
*“Some” is not a number.*  
*“Soon” is not a time.*



# 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**

# Learning Sessions





# Working With Patient and Family Advisors: Recruiting, Training, and Partnering

**Julie Barnes**

**Patient and Family Centered Care Manager**

**Wake Forest Baptist Medical Center**

**September 4, 2013**



Agency for Healthcare Research and Quality  
Advancing Excellence in Health Care • [www.ahrq.gov](http://www.ahrq.gov)



## Leading Partnerships with Patients & Families

Presented by: Sue Collier, MSN, RN, FABC  
Performance Improvement Specialist  
Patient-Family Engagement

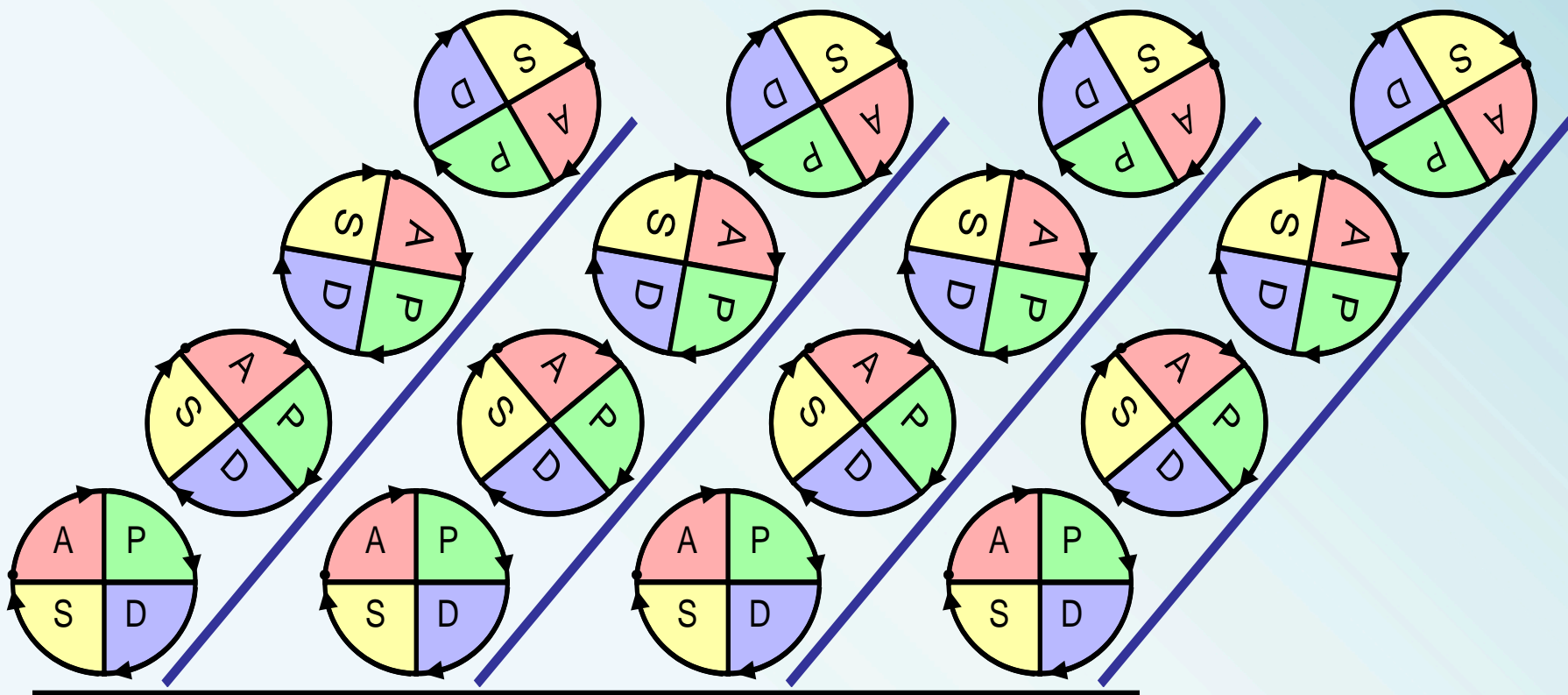
Perinatal Quality Collaborative of NC  
Learning Session 1  
September 4, 2013



North Carolina  
Quality Collaborative



# 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**



news	about	initiatives	partners	institutions	resources
NAC	CMOP	Patient/Family	National CQIG	FL/NC	MB/VA
MB/ACC	CQIG	IGIG	30 Weeks	How's Your Baby	
Immunization					

## Patient / Family Engagement

The three pillars of PQCNC are the spread of clinically effective, family centered and fiscally responsible care practices across the state of North Carolina. The collaborative is comprised of folks throughout the state of North Carolina who have a vested interest in PQCNC's mission including care providers, payors, family representatives, and other maternal and infant health leaders. PQCNC is deeply committed to partnering with family members and is looking to family members and family advocates to provide input as to the quality initiatives that would be most beneficial to families and, most importantly, to work as team members on these initiatives. In support of that aspect of our mission we are proud to convene and support the efforts of the Patient / Family Engagement Initiative. This is a very important part of PQCNC activities as the Patient / Family Engagement Initiative will provide additional ways for us to learn from each other and discuss ways to involve patients and families in order to improve health care delivery. Ideas exchanged through the Patient / Family Engagement Initiative will enhance the collaboration between families, care providers and other stakeholders involved in perinatal care at the state and local level as well as inform the work of every succeeding initiative that PQCNC undertakes.

For more information, to get involved, or to subscribe to updates of Patient / Family Engagement Group activities contact [Keith M. Collins](#).

### Updates

**Getting ready for kick off - August 2011**  
 August 15, 2011 - The Expert Team has completed an incredible amount of work over the past month to prepare for the Patient and Family Initiative Kickoff in September! The last four weeks have been spent defining the scope of the initiative. [Read more...](#)

**Patient / Family Engagement Expert Team Name - July 2011**

### Results

Results to date include the development of an action plan.



### Resources

- PFE Action Plan
- PFE Expert Team "Action Plan" Call
- PFE Learning Session 1 Registration
- PFE Expert Team "Report" Call
- The Role of Executive Support for Quality Improvement Initiatives
- National Quality Improvement Team - Ultimate Performance Quality Improvement Outcome Metrics

NAS	C-MOP	<b>Patient / Family</b>	National CABS	FL / NC	Milk-Well
Milk-NOOC	CABS	SMB	39 Weeks	How's Your Baby	

Immunization

## Patient / Family Engagement September Webinar

Next Webinar: Thursday, September 12, 2013 2:00 PM

Audio: 832.551.5100, passcode 222655#

[Click here to access Webinar](#)

Agenda:TBA

Using Elluminate:

Enter your name and click 'Login'

**lluminate Session Log In**

Please enter your Name for the session.

# Patient

The three pillars of P... collaborative is compr... representatives, and c... and family advocates... those initiatives. In su... very important part of... ways to involve patie... the collaboration betw... every succeeding initi...

For more information,

### Updates

**Getting ready for**

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[Read more...](#)

**Patient / Family Engagement Expert Team forms - July 2013**

July 13, 2013 - The Patient and Family

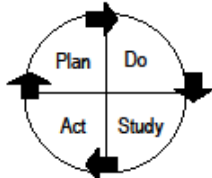
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### Resources

- PFE Action Plan
- PFE Expert Team "Action Plan" Call
- PFE Learning Session 1 Registration

[More Resources](#)

# 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



Navigation menu with buttons: NAS, C-MOP, Patient / Family (highlighted), National CABS, FL / NC, Milk-Well, Milk-NOCC, CABS, SIVB, 39 Weeks, How's Your Baby

Immunization

## PFE Action and Data Resources

The following documents are available to assist you in planning your work, understanding what to collect, collecting, and submitting your data:

- [PFE Action Plan](#)
- [PFE PDSA Worksheet](#)
- [PFE Team Planning Form](#)
- [PFE Monthly Data Collection Form](#)
- [PFE Data Dictionary](#)

# Patient

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**Patient / Family Engagement Expert Team forms - July 2013**  
July 13, 2013 - The Patient and Family



## Resources

- [PFE Action Plan](#)
- [PFE Expert Team "Action Plan" Call](#)
- [PFE Learning Session 1 Registration](#)

[More Resources](#)

**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





 [www.pqnc.org](http://www.pqnc.org)  
**PQCNC**

199 Days Since Last Infection

The Perinatal Quality Collaborative of North Carolina is committed to making North Carolina the best place to be born by promoting better outcomes for mothers and babies, better hospital experiences for families when babies are born and better value for each health care dollar.



Contact:  
Tara Bristol  
tara.bristol@pqcnc.org

