North Carolina Institute of Medicine Task Force on Patient & Family Engagement

Feb 18, 2014

Thoughts on Patient & Family Engagement

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CEO, Project Patient Care

What We Will Cover Today

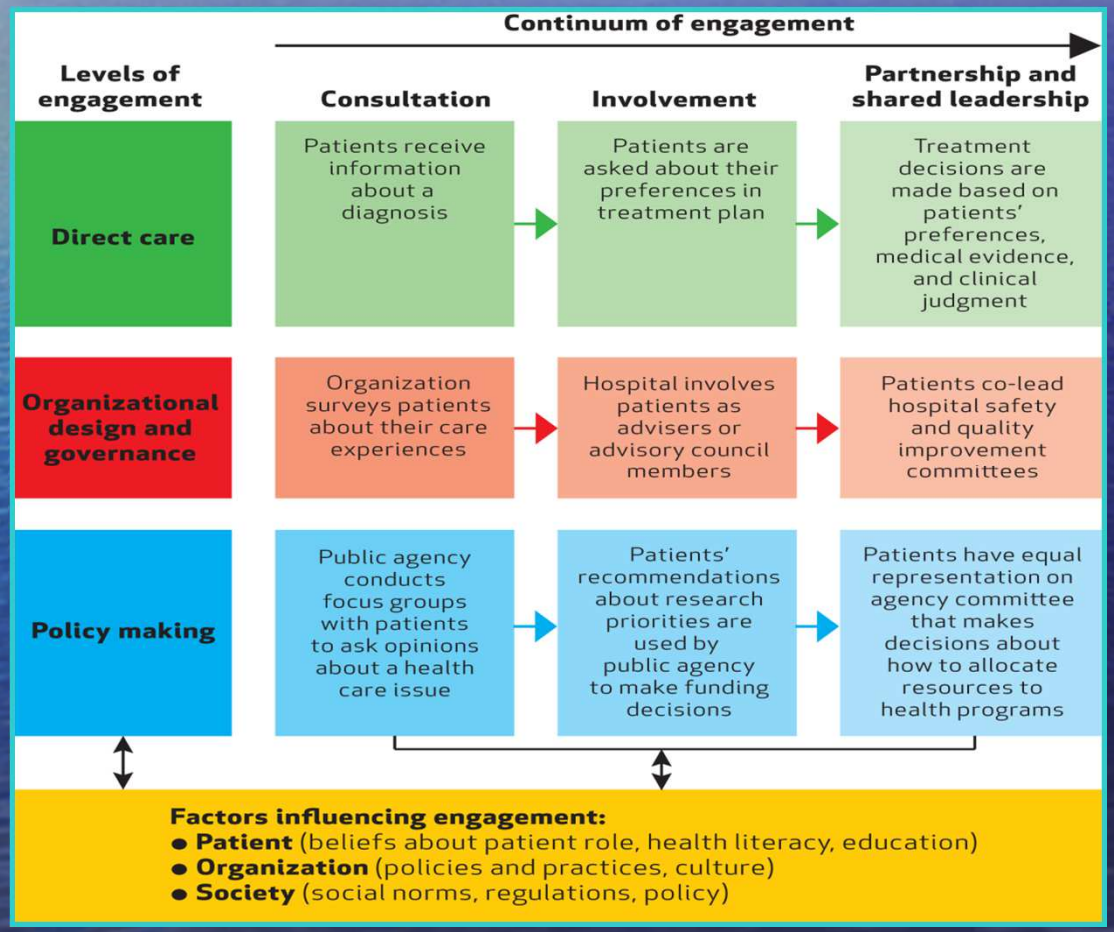
- PFE Frameworks & Concepts
- PFE and Patient Safety
- PFE as a "change engine" in the federal Partnership for Patients Campaign
- New developments in PFE
- Together making PFE work

Why Patient Engagement? Why Now?

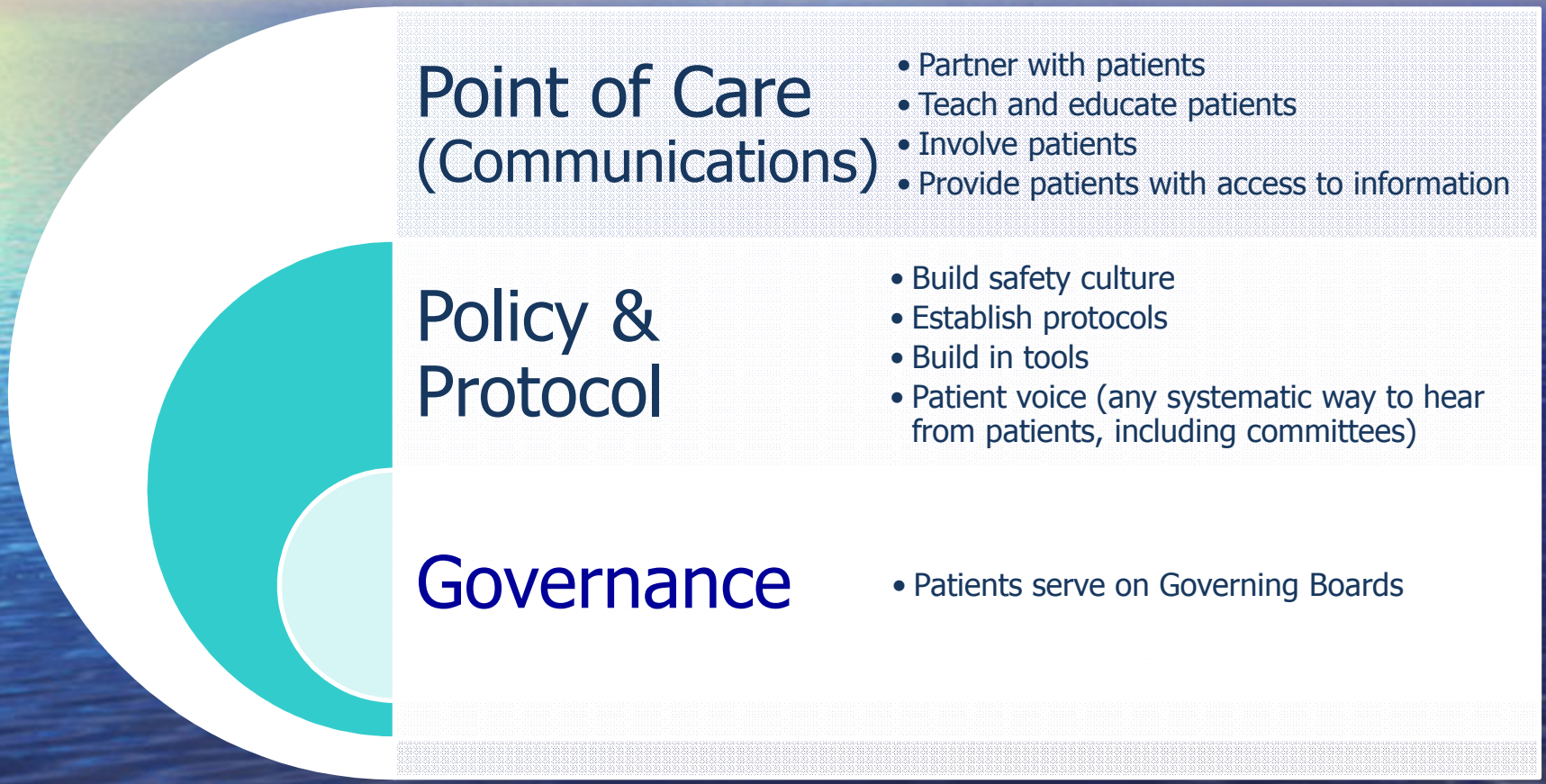
- Patient-centered care one of six Institute of Medicine aims (*Crossing the Quality Chasm*, 2001)
- The belief that patient engagement is the right thing to do.
- The belief that patient engagement can improve outcomes

Framework for Patient & Family Engagement

Karman KL et al, *Health Affairs* v. 32 no. 2 223-231 (2013)



PfP Framework Patient & Family Engagement



Point of Care (Communications)

- Partner with patients
- Teach and educate patients
- Involve patients
- Provide patients with access to information

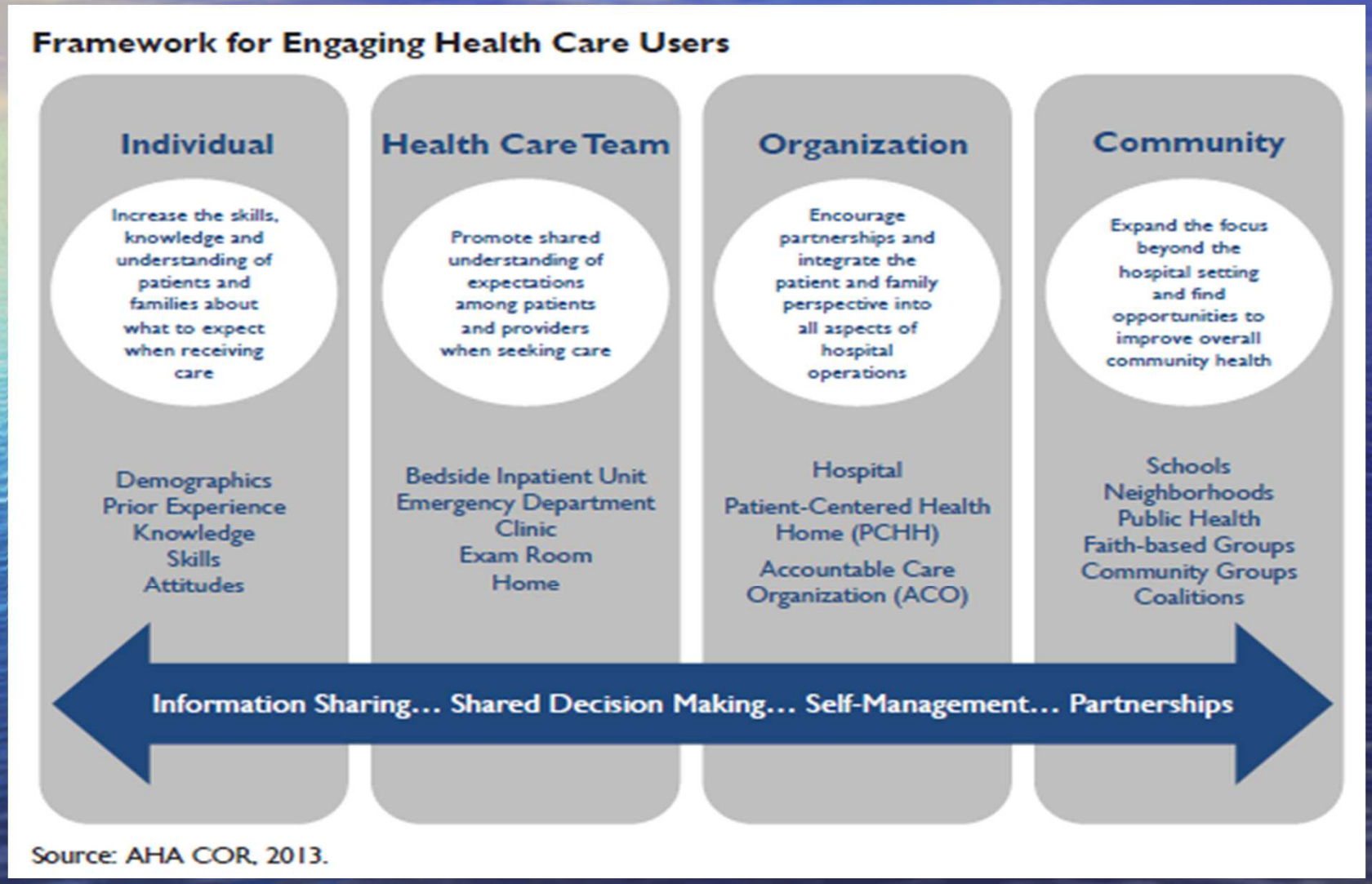
Policy & Protocol

- Build safety culture
- Establish protocols
- Build in tools
- Patient voice (any systematic way to hear from patients, including committees)

Governance

- Patients serve on Governing Boards

AHA's PFE Framework



What is Patient & Family Centered Care?

- Goal = bringing patient/family perspective into planning, delivery, evaluation of care
- Key Concepts:
  - Dignity & respect
  - Information sharing
  - Participation opportunities
  - Collaboration

What is Patient Centered Care?

According to Wikipedia the four attributes of PCC are…

- "Whole-person" care.
- Coordination and communication
- Patient support and empowerment
- Ready access

Bechtel, Christine. "If You Build it, Will They Come? Designing Truly Patient-Centered Health Care". *Health Affairs*., 2011-03-25.

What is Patient Centered Care?

According to Berwick, PCC should be…

The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care.

Berwick, Donald. *What Patient-Centered Should Mean: Confessions of an Extremist*. *Health Affairs,* 25 March 2011.

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What is Patient Centered Care?

Picker Institute claims to have originated the concept with 8 Principles of PCC…

1. Respect for patients' values, preferences and expressed needs
2. Coordination and integration of care
3. Information, communication and education
4. Physical comfort
5. Emotional support and alleviation of fear and anxiety
6. Involvement of family and friends
7. Transition and continuity
8. Access to care

Through the Patient's Eyes. *Picker Institute, 1*993.

What is Patient Centered Care?

Picker Institute's most recent definition…

1. Informing and involving patients, eliciting and respecting their preferences
2. Responding quickly, effectively and safely to patients' needs and wishes
3. Ensuring that patients are treated in a dignified and supportive manner
4. Delivering well coordinated and integrated care

Picker Institute, 2004.

What is Patient Centered Care?

International Association of Patient Organizations mapped common elements…

1. Education/Shared knowledge
2. Involvement of family and friends
3. Collaboration/team management
4. Holistic/sensitive to non-medical or spiritual issues
5. Respect for a patient's needs and wants
6. Free flow/accessibility of information

What is Patient-Centered Healthcare? A Review of Definitions and Principles. *IAPO, 2007*.

What is Patient Centered Care?

IAPO also identified these curious omissions from most definitions…

1. PCC as a patient right
    1. Implicit?
    2. Framing too antagonistic?
    3. Covered by human rights laws, declarations & treaties?
2. Patient responsibility for their own health care
3. Evidence based care
4. Patient safety

What is Patient-Centered Healthcare? A Review of Definitions and Principles. *IAPO, 2007*.

Universal Declaration of Human Rights
(Dec 10, 1948)

- Preamble:

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom.

- Article 25:

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services…

International Covenant on Economic, Social & Cultural Rights
(Dec 16, 1966)

Article 12

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

   (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

   (b) The improvement of all aspects of environmental and industrial hygiene;

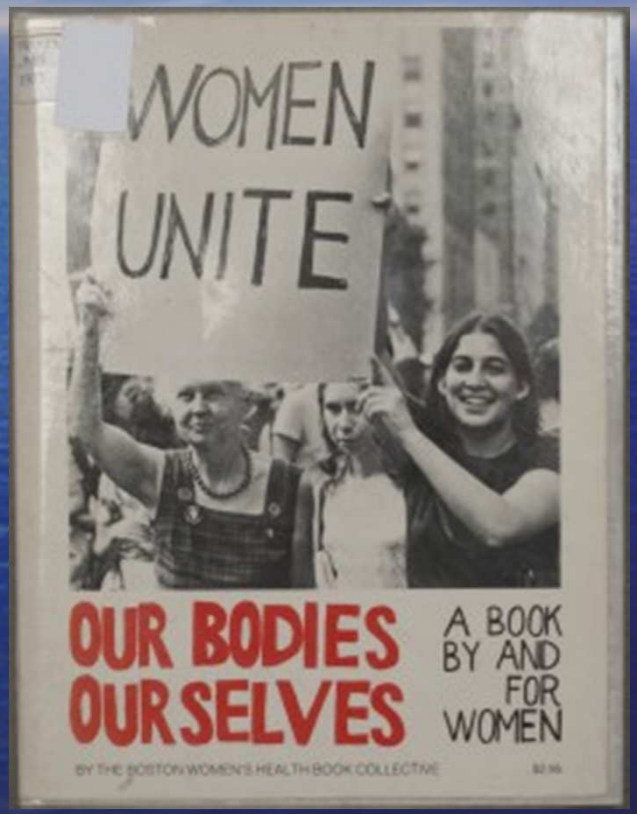
   (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

   (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

European Charter of Patients Rights
14 Immutable Rights (2002)

- **Right to preventive measures**
- **Right of access**
- **Right to information**
- **Right to consent**
- **Right to free choice**
- **Right to privacy and confidentiality**
- **Right to respect for patients' time**
- **Right to observance of quality standards**
- **Right to safety**
- **Right to innovation**
- **Right to avoid unnecessary suffering and pain**
- **Right to personalised treatment**
- **Right to complain**
- **Right to compensation**

Patient-Centered Care Means Sharing Power*



*Except when it doesn't

Patient Centered Care Manifest

- Patient Satisfaction
- Outcomes Improvement
- Patient and family engagement
- Health equity
- Access to health records
- Shared/informed decision-making
- PCORI
- Personalized medicine
- And?

One More Concept: Disclosure

- Informing patients and families of unexpected adverse events
- Terminology not always used consistently
- Rules of thumb:
  - how would I want to be treated?
  - what is the right thing to do?

Why Don't Providers Disclose? Four Barriers

- **Education Barrier**: They aren't confident in their skills
- **Fear to Harm Barrier**: They fear causing further harm to patients
- **Trauma Barrier**: They actively fear litigation, reputation loss, emotional distress or other harm to self
- **Cultural Norms Barrier**: They are advised not to do it (or are indirectly discouraged by organizational or peer culture)

Partnership for Patients (PfP) 40/20/13 Breakthrough Aims

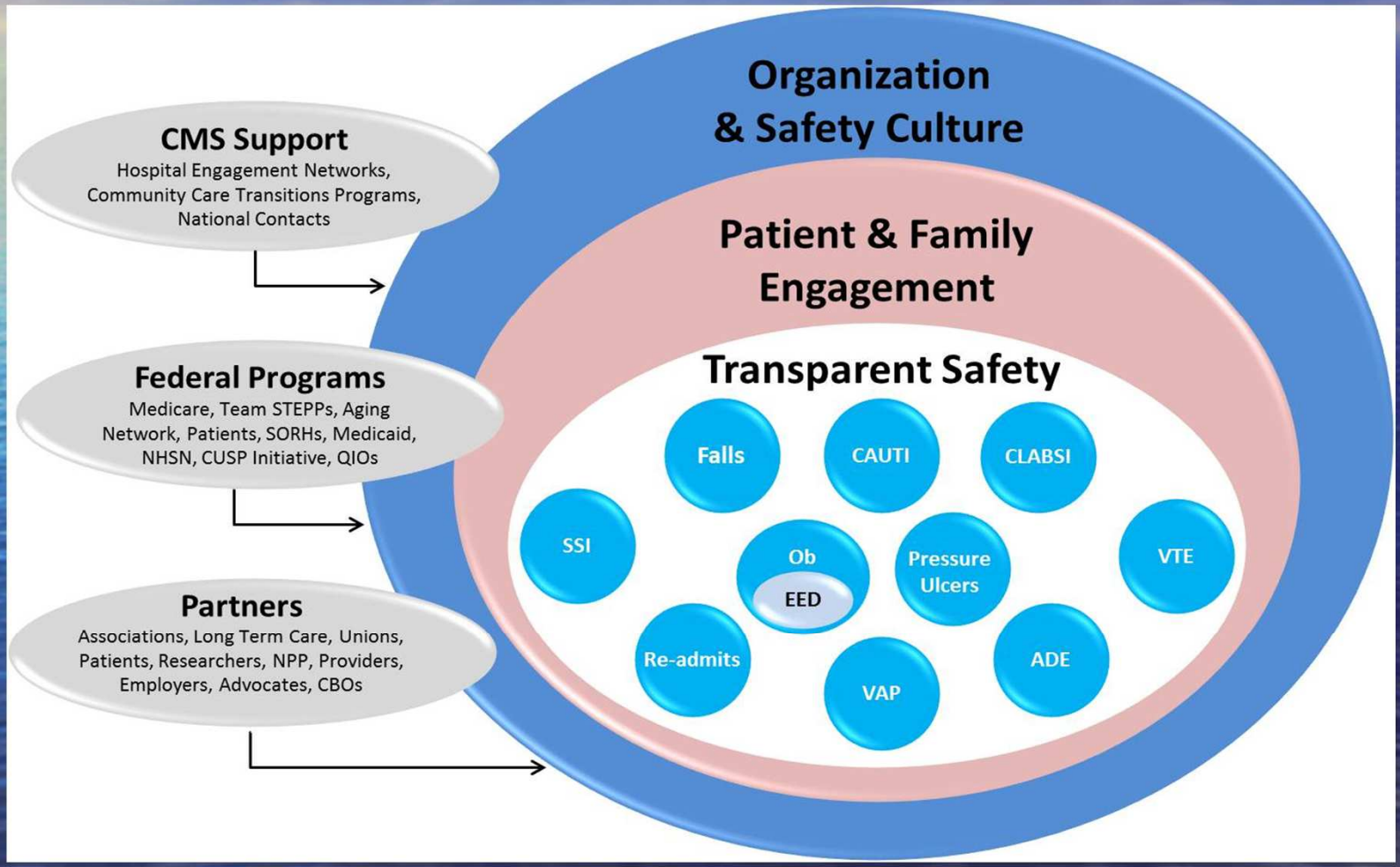
- Launched in April 2011
- 40% Reduction in Preventable Hospital Acquired Conditions by year-end 2013
- 20% Reduction in 30-Day Readmissions by year-end 2013
- Up to $35 Billion Dollars Saved

http://partnershipforpatients.cms.gov/

PfP Ten Original Areas of Focus

1. Adverse Drug Events (ADE)
2. Catheter-Associated Urinary Tract Infections (CAUTI)
3. Central Line Associated Blood Stream Infections (CLABSI)
4. Injuries from Falls and Immobility
5. Obstetrical Adverse Events - including elimination of Early Elective Deliveries before 39 weeks (EED)
6. Pressure Ulcers
7. Surgical Site Infections (SSI)
8. Venous Thromboembolism (VTE)
9. Ventilator-Associated Pneumonia (VAP)
10. Reducing Readmissions

PfP Campaign at a Glance



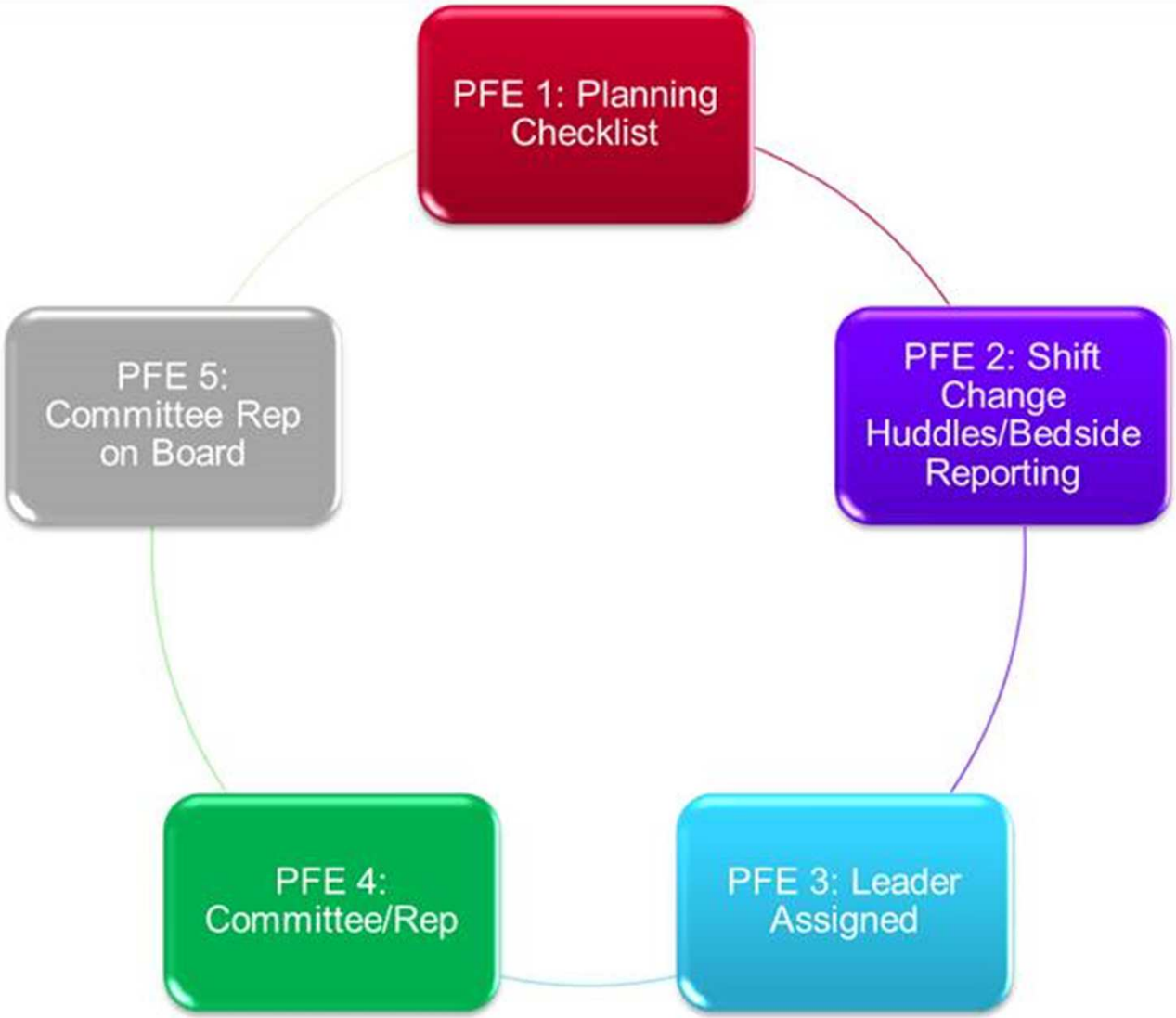
Leading Edge Advanced Practice Topics (LEAPT)

- **Severe Sepsis and Septic Shock (mandatory)**
- Clostridium Difficile
- Hospital-Acquired Acute Renal Failure
- Airway Safety
- Iatrogenic Delirium
- Procedural Harm (pneumothorax, bleed, etc.)
- Undue Exposure to Radiation
- Failure to Rescue
- Results Beyond the 40/20 Aims on HACs and readmissions
- Hospital Culture of Safety – Including Worker Safety
- Cost Savings Calculations for HACs

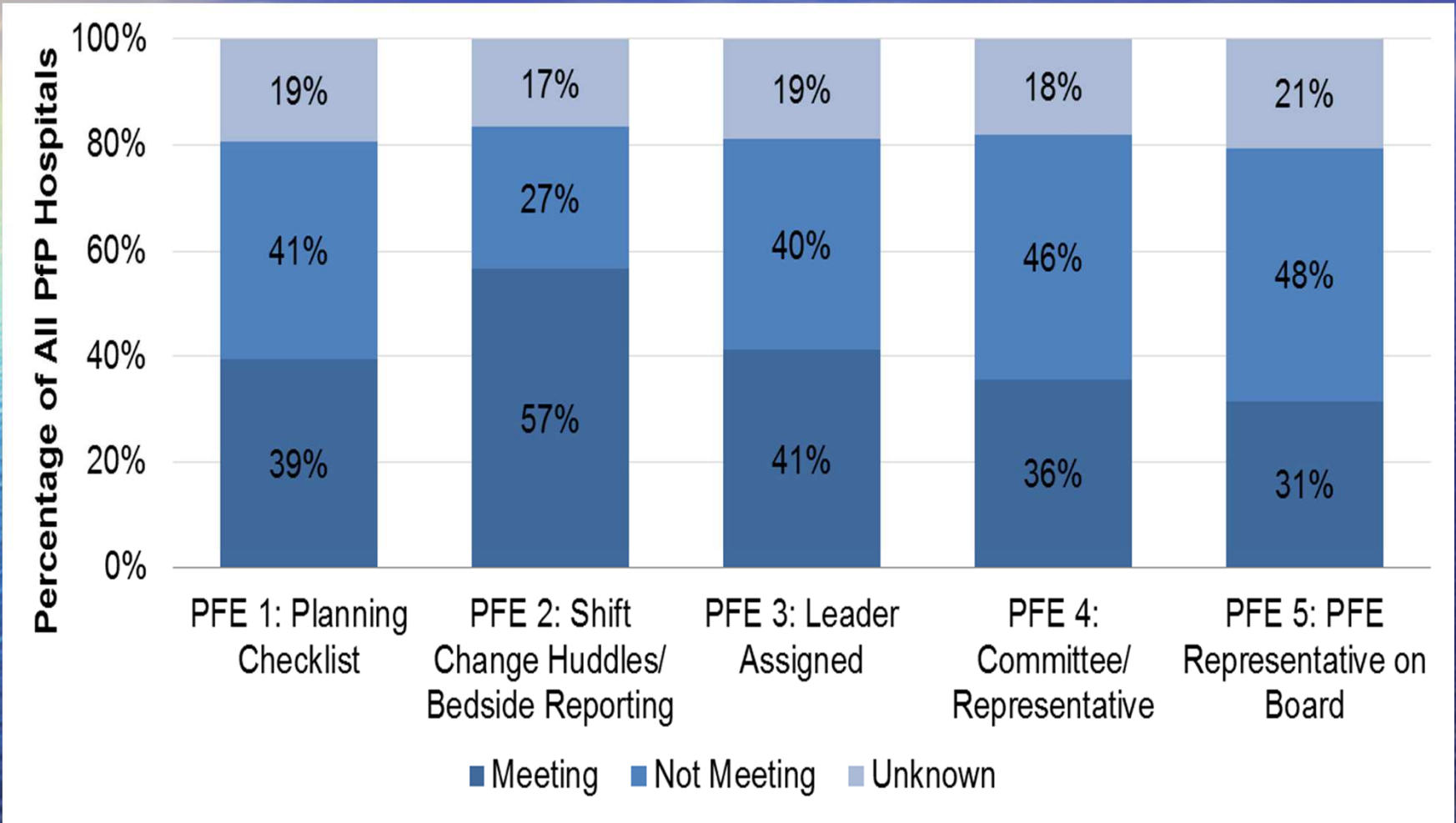
PfP PFE Metrics

Best Practice Category	PFE Metric Instruction: For each of the following items, indicate if the hospital does this or does not do this. If you do not know, indicate so. •Does=1 •Does not=0 •Unknown=u
Point of Care	1. Prior to admission, hospital staff provides and discusses a discharge planning check list with every patient that has a scheduled admission, allowing questions or comments from the patient or family (e.g., the planning checklist may be similar to the CMS Discharge Planning Checklist).
	2. Hospitals conduct both shift change huddles for staff and do bedside reporting with patients and family members in all feasible cases.
Policy & Protocol	3. Hospital has a dedicated person or functional area that is proactively responsible for Patient and Family Engagement and systematically evaluates Patient and Family Engagement activities.
	4. Hospital has an active Patient and Family Engagement Committee (PFEC) OR at least one former patient that serves on a patient safety or quality improvement committee or team.
Governance	5. Hospital has one or more patient(s) who serve on a Governing and/or Leadership Board and serves as a patient representative.

Patient and Family Engagement Metrics

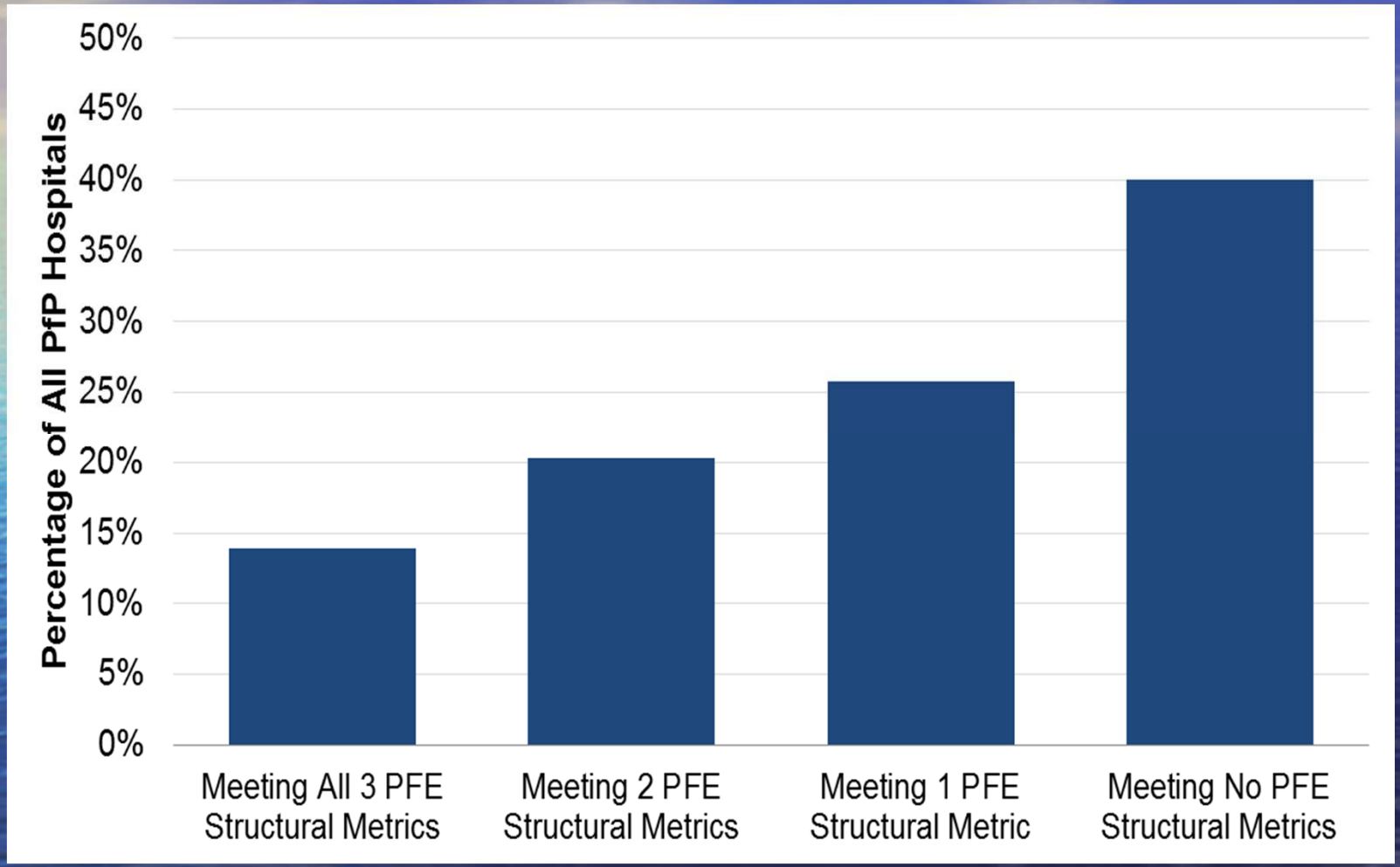


PFE Progress (Dec 2013)



Source: Z-5 Spreadsheets, n = 3,720 HEN-aligned hospitals

PFE Structural Metrics, Dec 2013



Source: Z-5 Spreadsheets, n = 3,720 HEN-aligned hospitals

Carolinas Health System Metrics

Measure	CHS P&FE High Performers Baseline (2010)	CHS P&FE High Performers Results (Jan 2012-May 2013)	CHS P&FE High Performers Reduction Percentage	Other CHS Hospitals Baseline (2010)	Other CHS Hospitals Results (Jan 2012-May 2013)	Other CHS Hospitals Reduction Percentage
Number of falls with injury per 1,000 patient days (NDNQI)	0.08 (19/226,467)	0.05 (17/323,495)	**- 37.36%**	0.11 (51/462,415)	0.13 (124/943,194)	**+ 19.20%**
PSI 12: Post-operative Pulmonary Embolism or DVT	4.09 (58/14,191)	2.95 (64/21,695)	**- 27.82%**	4.44 (147/33,115)	3.94 (173/43,948)	**- 11.32%**
Early Elective Delivery (PC-01)	3.54% (42/1,188))	1.13% (17/1,505)	**- 68.05%**	11.32% (474/4,188)	3.64% (172/4,724)	**- 67.83%**
PSI 18: Obstetric Trauma: Vaginal Delivery w/ instrument	198.92 (37/186)	127.06 (54/425)	**- 36.13%**	165.19 (205/1241)	145.92 (245/1,679)	**- 11.66%**

Safety Across the Board (SAB) Initiative

Designed to:

- Measure and track total patient harm as a composite
- Connect the dots so improvement work is not just projects & projects
- Provide big picture that engages all staff, leadership and governance
- Instill strategies that survive the PfP Campaign

New Developments
HRET SAB Governance Initiative

- Will rollout this quarter
- Focused on "eliminating Harm Across the Board" = "achieving SAB
- Intregrates SAB, Accountability, PFE and Health Equity
- Goals:
  - 1000 SAB stories by October 2014
  - Monthly SAB story with a PFE component submitted to hospital BoDs

New Developments Expected New Data

- National Patient Safety Foundation White Paper on PFE Evidence to be published Feb 2014
- National survey of PFE practices to be published by HRET by May

New Developments
PfP PFE Metrics

Point of Care	*Policy, Protocol*	*Governance*
PFE 1: Planning Checklist w Patient & Family	***PFE 3:*** PFE Proactive Responsibility	***PFE 5***: Patient Representative On Board
PFE 2: Shift Change Huddles/Bedside Reporting	***PFE 4***: Active PFE Committee Or Advocate	

New Developments
Add Two New PFE Criteria?

- PFE Advocates Are Trained in *Safety Across the Board*
- Medication reconciliation with the patient and family within 5 days of discharge

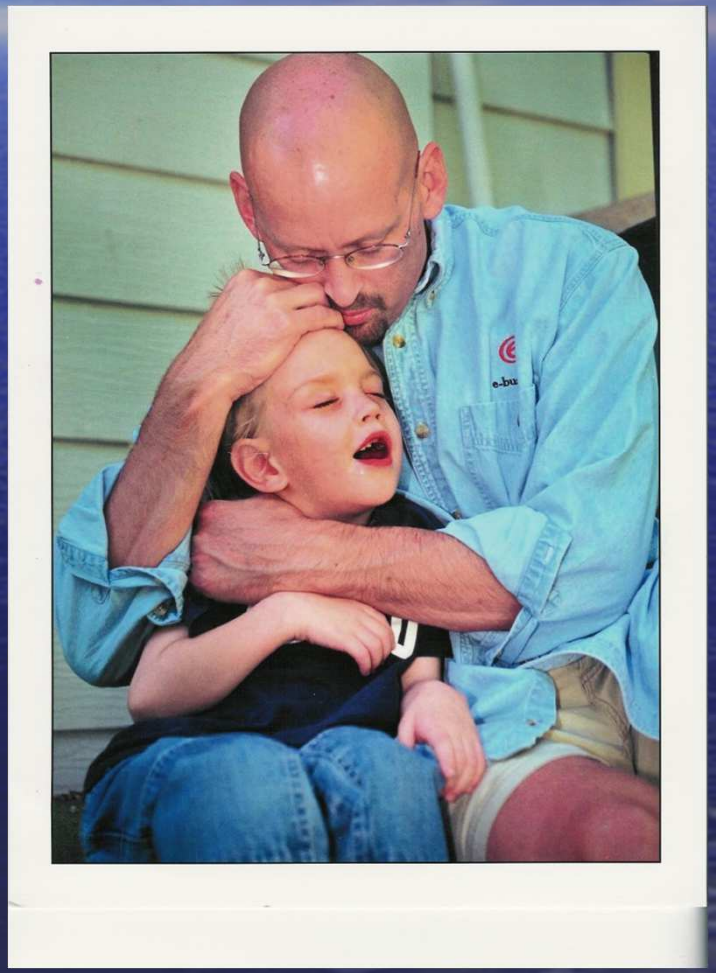
Align the PFE Criteria and Leadership Criteria as a hospital safety culture check list?

New Developments
PfP PFE Metrics

Point of Care	*Policy, Protocol*	*Governance*
PFE 1: Planning Checklist w Patient & Family	***PFE 4:*** PFE Proactive Responsibility	
PFE 2: Shift Change Huddles/Bedside Reporting	***PFE 5***: Active PFE Committee Or Advocate	***PFE 7***: Patient Representative On Board
PFE 3: Post Discharge Med Rec w Family	***PFE 6:*** PFE Advocates Are SAB Trained	

Together Making PFE Work
Sue Sheridan, Boise, ID

- Neonatal jaundice guidelines relaxed 1994
- Cal Sheridan suffers brain damage on 6th day of life March 1995
- AHRQ/QUIC testimony September 2000
- HCA internal surveillance shows 1.2 per month at risk May - December 2004
- HCA announces findings June 2005



American Academy of Pediatrics Jaundice Advice @ 2000

What effect does breastfeeding have on jaundice?

Most breastfed babies do not have a problem with jaundice that requires interruption of breastfeeding. However, if your baby develops jaundice that lasts a week or more, your pediatrician may ask you to temporarily stop breastfeeding for a day or two. If you must temporarily stop breastfeeding, talk to your pediatrician about pumping your breasts so you can keep producing breast milk and can restart nursing easily.

If your baby has jaundice, do not be alarmed. Remember that jaundice in a healthy newborn is not serious and usually clears up easily. If your baby has a very serious case of jaundice and other medical problems, your pediatrician will talk to you about other treatments.

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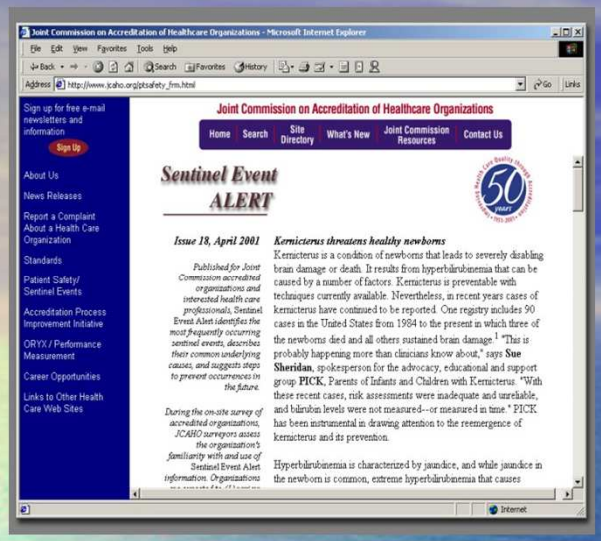
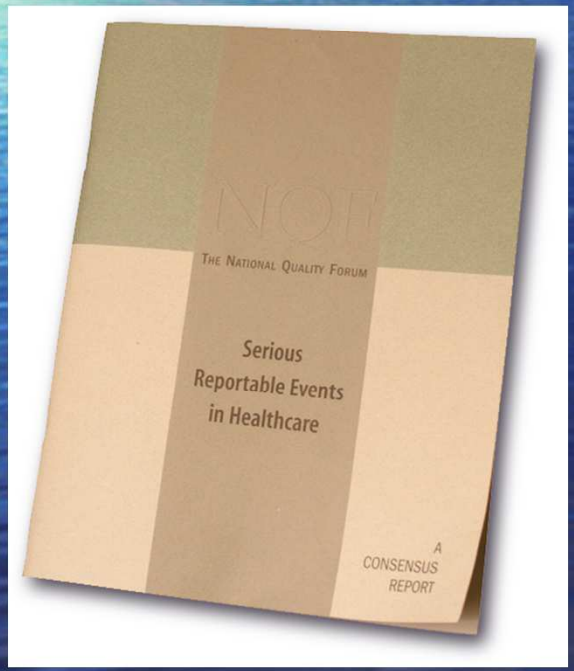
http://www.aap.org/family/jaundice.htm

1/15/01





Test delayed: Pat Sheridan sued a Boise hospital and pediatrician, saying son Cal wasn't given a blood test soon enough after birth to detect dangerously high levels of bilirubin. Cal, now 5, has brain damage.

Porous safety net allows lethal medical mistakes

Care has failed to keep up with technological advances

By Robert Davis and Julie Appleby
USA TODAY

Special Report
To err can be deadly

- Sharing data could save lives. Story, 1B
- Talk live at 1 p.m. ET today at talk.usatoday.com

An overworked nurse infuses the wrong type of blood into a patient. An experienced pharmacist puts the wrong drug in a child's medicine bottle. A less experienced surgeon blows a heart procedure that is performed more frequently, and flawlessly, down the street.

All the patients die, victims of medical errors. Up to 98,000 such deaths a year — perhaps the nation's most disturbing health care statistic — have health officials scrambling to find fixes. They are spurred by an Institute of Medicine report last November that named errors made by doctors, nurses and hospital workers the USA's eighth-leading killer.

What they have discovered are glaring problems in the health care system, many of which are expected to be at the heart of a new institute report in the next few months. Among them:

► Too many modern drugs and treatments for doctors to keep in mind as they rush from patient to patient.

► Nurses taking on more work as pharmacies and other hospital departments close early or reduce their staffs to save money.

► A shift toward performing more surgeries in less regulated facilities outside hospitals, such as doctors' offices and clinics, putting patients at greater risk.

► In perhaps the most worrisome development, a slowness by the medical community to embrace technology that could help doctors avoid errors. Not only does the situation create more risk for patients, but it has slowed progress. The federal government has declined to approve some drugs, for example, because it can't trust doctors to remember their complexities.

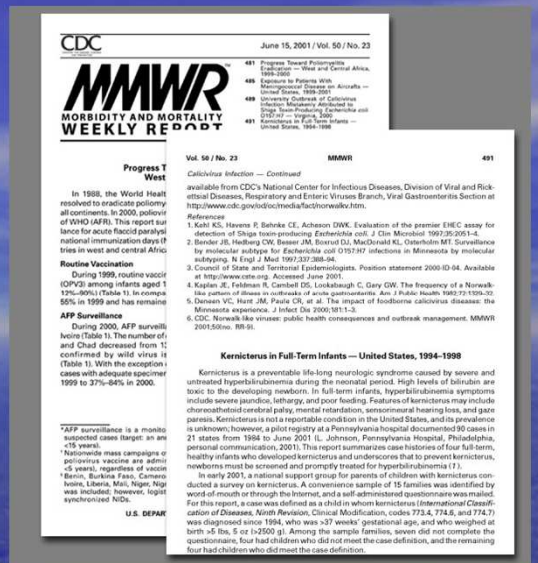
"Medicine, the way it's practiced in the United States today, can be pretty unsafe," says Andrew Wiesenthal, a Permanente Federation doctor who is overseeing the development of a computer system to help Kaiser Permanente practice safer medicine.

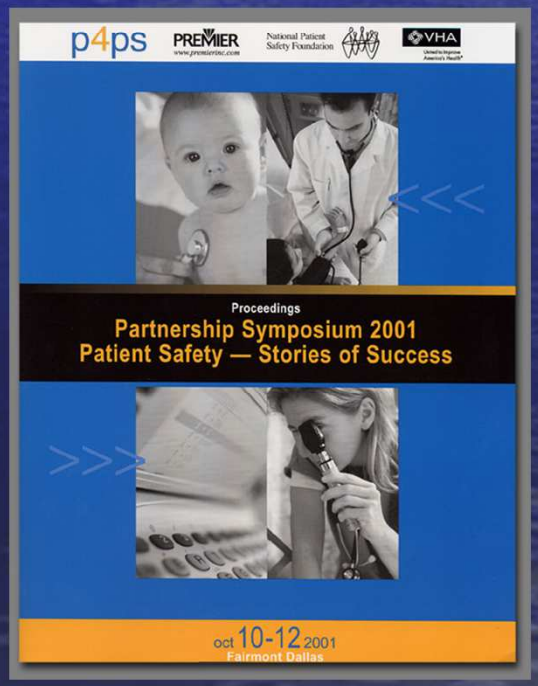
Improvements must be made, he says. "There is a moral imperative about it."

He and others are following the technological success of the Veterans Affairs hospital in Washington, D.C., where physicians use a $365,000 computer system that scans bar codes on patient bracelets and medicines.

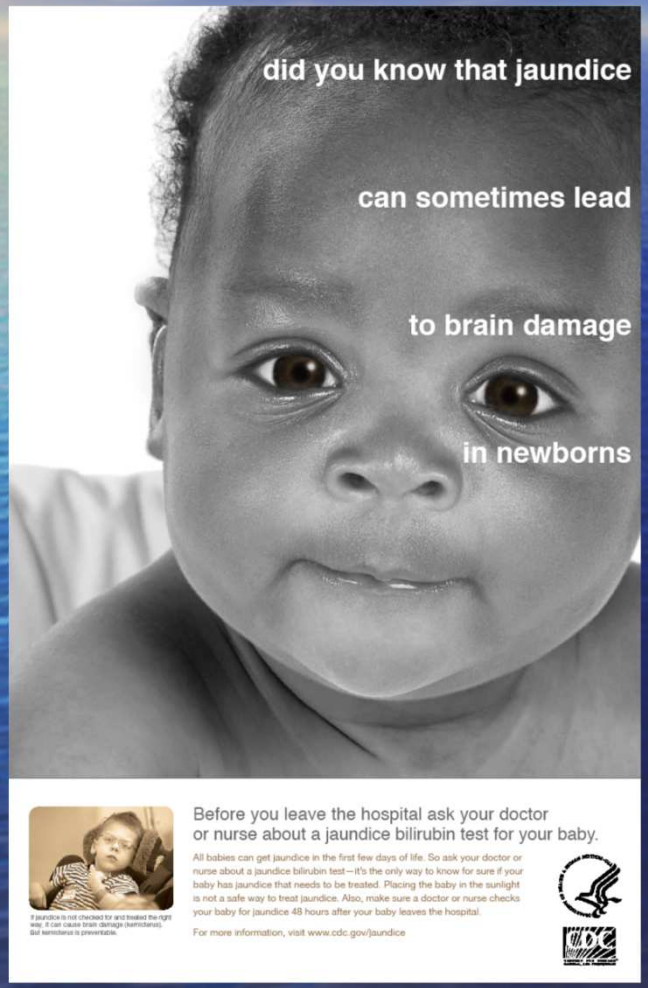
If a doctor is about to make a mistake,

Please see COVER STORY next page ►





Kernicterus Prevention Education Campaign



The Power of Partnership

"Mrs. Sheridan, I am the guy who stood up at the HCA PRMI Congress VIII and promised you we'd change our hospital rules within one week to include universal bilirubin screening at Conroe Regional Medical Center. Well, we did it. All babies will be screened at about 24 hours, and plotted on the nomogram, with followup from that as needed. We have empowered nurses to order bilirubins on babies without a doctor's order (or, technically, with our department's standing order).

To my knowledge, we have been lucky so far. However, how can you know for sure? Maybe there's a baby or two minimally affected whose problem hasn't been figured out to be kernicterus.

Would you tell Cal about this? And realize that if you hadn't come to the Congress, it wouldn't have been done."

...8/25/05 email from Gerald L Bullock, MD, JD, FACOG
Chairman, Department of Ob/Gyn/Pedi, Conroe Regional Medical Center

Together Making PFE Work

Bob & Barb Malizzo

Timothy McDonald, MD, JD

University of Illinois Hospital & Health Sciences System

Michael Phillips' review in A+E

Chicago Tribune

Questions? Call 1-800-Tribune | Friday, October 7, 2011 | Breaking news at chicagotribune.com

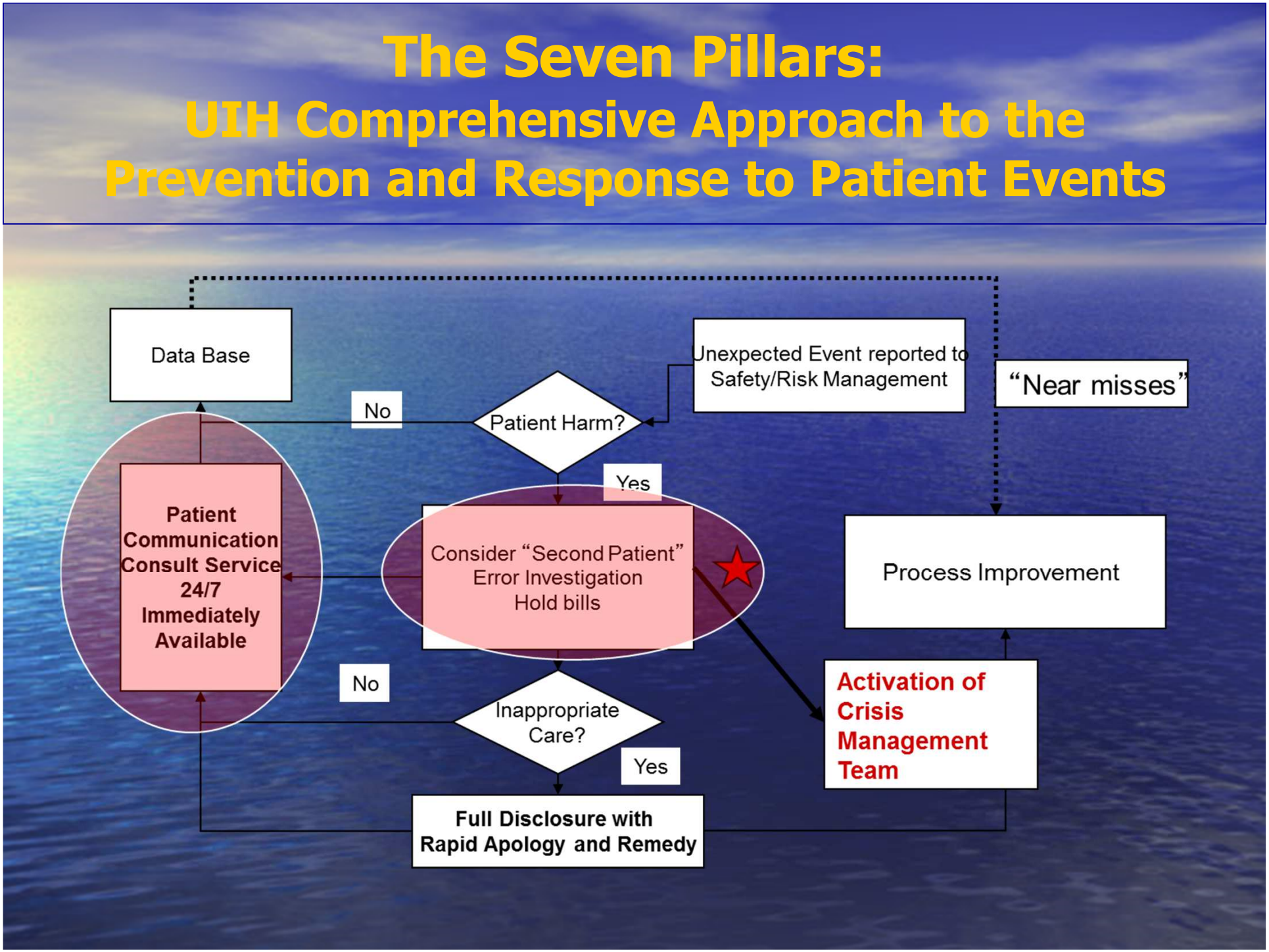
October 7, 2011

HEATHER CHARLES/TRIBUNE PHOTOS

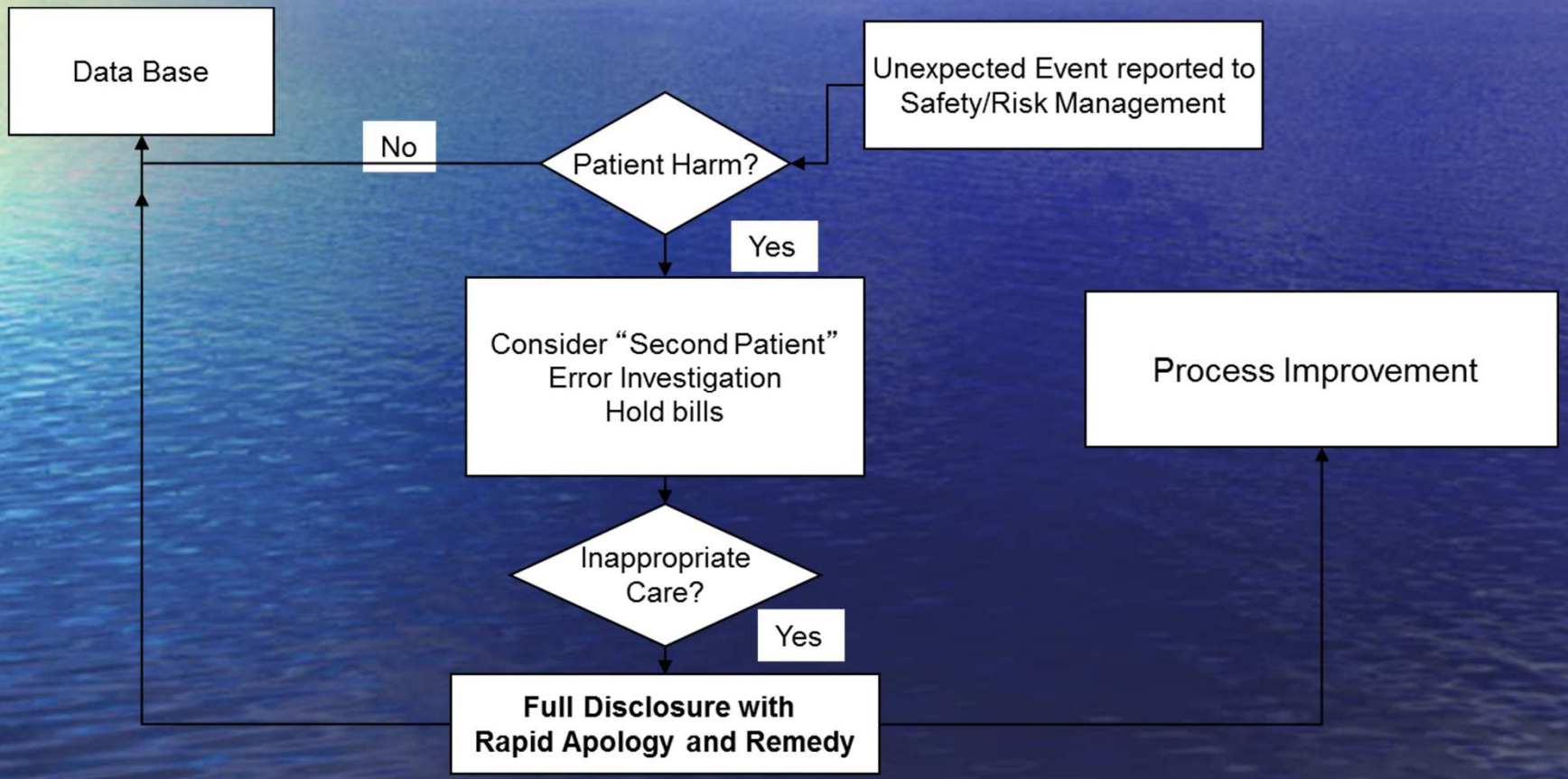
Bob and Barb Malizzo, along with daughter Kristina Chavez and her son Adrian, visit their daughter Michelle Ballog's grave at Graceland Cemetery in Valparaiso, Ind. Ballog died after a medical error at UIC Medical Center in Chicago.

Family lends hand after deadly error

The Seven Pillars:
UIH Comprehensive Approach to the Prevention and Response to Patient Events



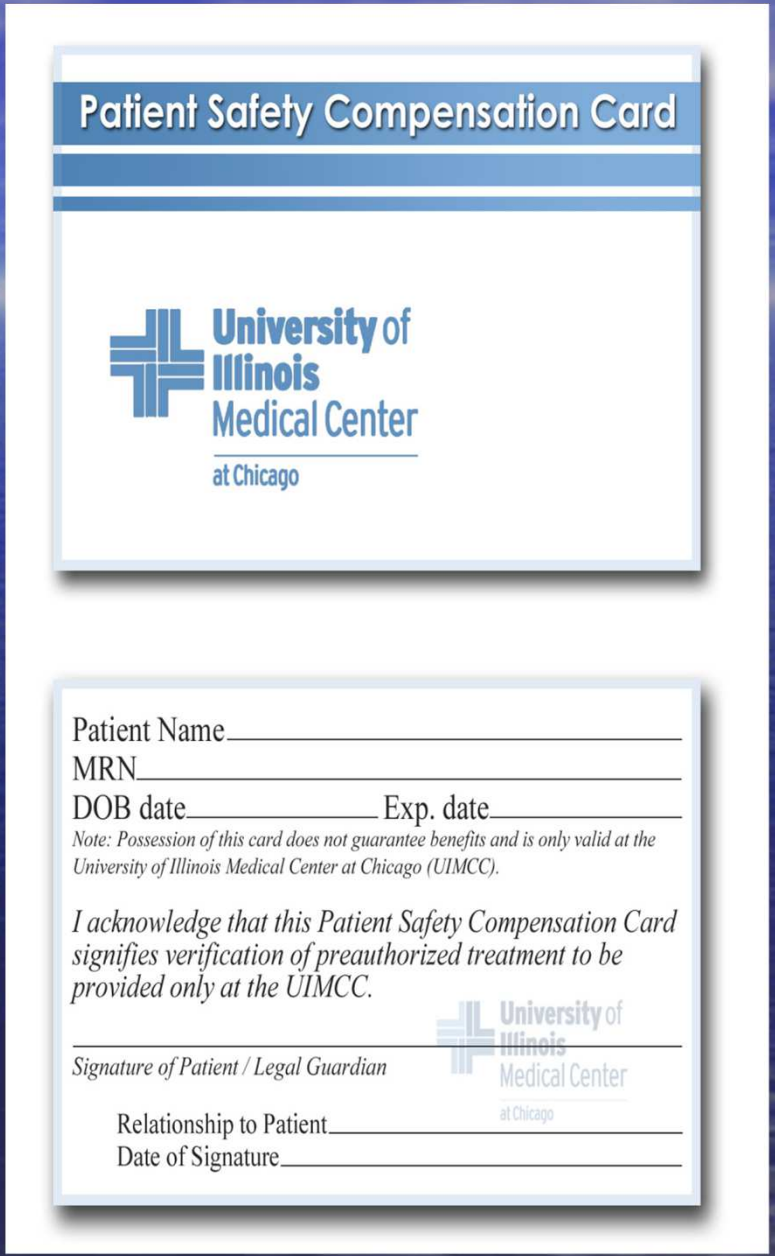
The Original UIH Seven Pillars Model



Communication + Compensation = Savings

Win/Win/Win/Win:

- Used only when inappropriate care
- Patient and family-centered
- Accountable AND removes health $ from liability damages calculus
- Trust & reputation increased
- Malizzo case
  - >$200,000 hospital fees
  - >$25,000 in professional fees



Process Improvement: Change in National Guidelines

- July 1, 2011, ASA
- Specifically, in section 3.2.4 of the Standards for Basic Anesthetic Monitoring, the ASA states, "...During moderate or deep sedation the adequacy of ventilation shall be evaluated by continual observation of qualitative clinical signs and **monitoring for the presence of exhaled carbon dioxide** unless precluded or invalidated by the nature of the patient, procedure, or equipment.

QualityNet 2011

Together Making PFE Work
Roxanne Goeltz, Minneapolis, MN

- Air Traffic Controller
- Brother Mike passed away September 1999
- Minnesota Alliance for Patient Safety
- Roxanne's cancer diagnosed April 2000
- Open chest surgery July 2000
- Pulmonary embolism the day after surgery
- U.S. Senate testimony June 2000

Goeltz Guide to Team Building

Pick the right people

Every team needs a captain (it might be you)

Help me be the best patient I can be

Get to know each other

200% accountability

Mind the gaps

Be nice

Goeltz U.S. Senate Testimony June 11, 2003

I suffered a pulmonary embolism my second day in the hospital. Many nurses have tried to convince me it was the fault of the RN on duty that day. I do not believe that for one minute. She was covering twice the number of patients she should have, and I was not educated to the fact of how important it was to get up as soon after surgery as possible.

Later, a doctor specializing in this area indicated to me that this clot was waiting to happen and the surgery just hurried it along.

I was fortunate to be in the hospital when it happened. The nurse should not be blamed for this outcome. I believe the system failed her.

Together Making PFE Work
Knitasha Washington Chicago, IL

- Anthony Washington passes away August 2009
- Knitasha starts Health Equity PhD program 2010, completed May 2013
- Mission to get hospitals to track outcomes by race/ethnicity
- Several Chicago hospitals now doing it
- PfP spreads request nationwide

Together Making PFE Work
Carol Levine, NY, NY

- Director, Families and Health Care Project, United Hospital Fund
- Phenomenal advocate for family members managing elder care
- "Find the 'right' family members"
- Work with NY Methodist produced dramatic reduction in readmissions
- www.nextstepincare.org

Together Making PFE Work
Teresa Pasquini, Martinez, CA

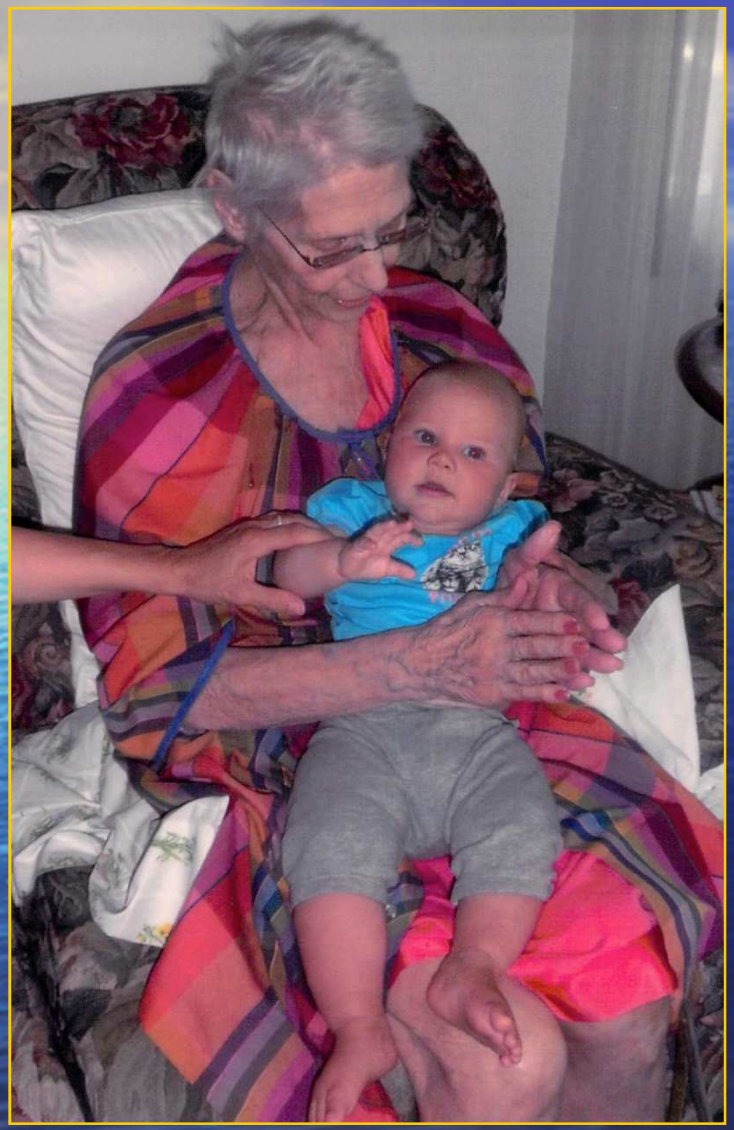
- Caregiver for son with schizophrenia
- Co-led Contra Costa hospital effort to redesign ED for persons with mental illness
- Adapted "Community Living Room" to outreach and recruit for PFAC

Together Making PFE Work
Hatlie Family, Mound, MN

- Mother & Step-Dad both early 80s, both with cancer 2009-2010
- Both had lost first spouses to cancer 20 years earlier
- July 2010 – Bob in remission, Mom failing
- Complex family differences and dynamics
- Family team with a goal: "The health care system will work for us."

What Birdie Wanted

1. Stay alive long enough to take care of Bob
2. Say goodbyes
3. Die at home
4. Meet baby Iola



Reaching Mom's Goals

- It takes a team [not a lone advocate]
- Be empathetic, but be in action
- Good cop, bad cop
- Don't wait for the invitation
- Don't assume the system works well
- Question the rules
- Value your health care providers & show them you care

The New Relationship

Each patient carries his own doctor inside him. They come to us not knowing that truth. We are at our best when we give the doctor who resides within each patient a chance to go to work.

Albert Schweitzer

What We Covered Today

- PFE Frameworks & Concepts
- PFE and Patient Safety
- PFE as a "change engine" in the federal Partnership for Patients Campaign
- New developments in PFE
- Together making PFE work

Thank you, and…

Peter Argenta, MD
Cathleen Chen, MD
Park Nicollet Frauenshuh Cancer Center
& Home Hospice