

# PERSON AND FAMILY CENTERED CARE IN A GLOBAL CONTEXT

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# Objectives

- What is person and family centered care (P&FCC)?
- How can we engage persons and their families in culturally sensitive and meaningful ways?
- What can leaders do to promote true partnerships with the person and his/her family as “full partners and sources of control?”

# Definitions of P&FCC

According to the International Alliance of Patients' Organizations (IAPO)

- *Patient-centred healthcare* – “healthcare that is designed and practiced with the patient at the centre”
- “...the patient is the only person in a position to make the decision on what [this] means to them, as an individual in the treatment of their condition and the living of their life”

# Other definitions -

## Institute of Medicine (IOM) –

“providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all decisions”

## Quality and Safety Education for Nurses (QSEN) –

“recognize the patient or designee as the source of control and full partner in providing compassionate and coordinated care based on respect for patients’ preferences, values and needs”

# Dimensions of PFCC

(Gerteis, Edgman-Levitan, Daley and Delbanco, 1993)

- Respect the patients' values, preferences and expressed needs
- Coordination and integration of care
- Information, communication and education
- Physical comfort
- Emotional support
- Involvement of family and friends

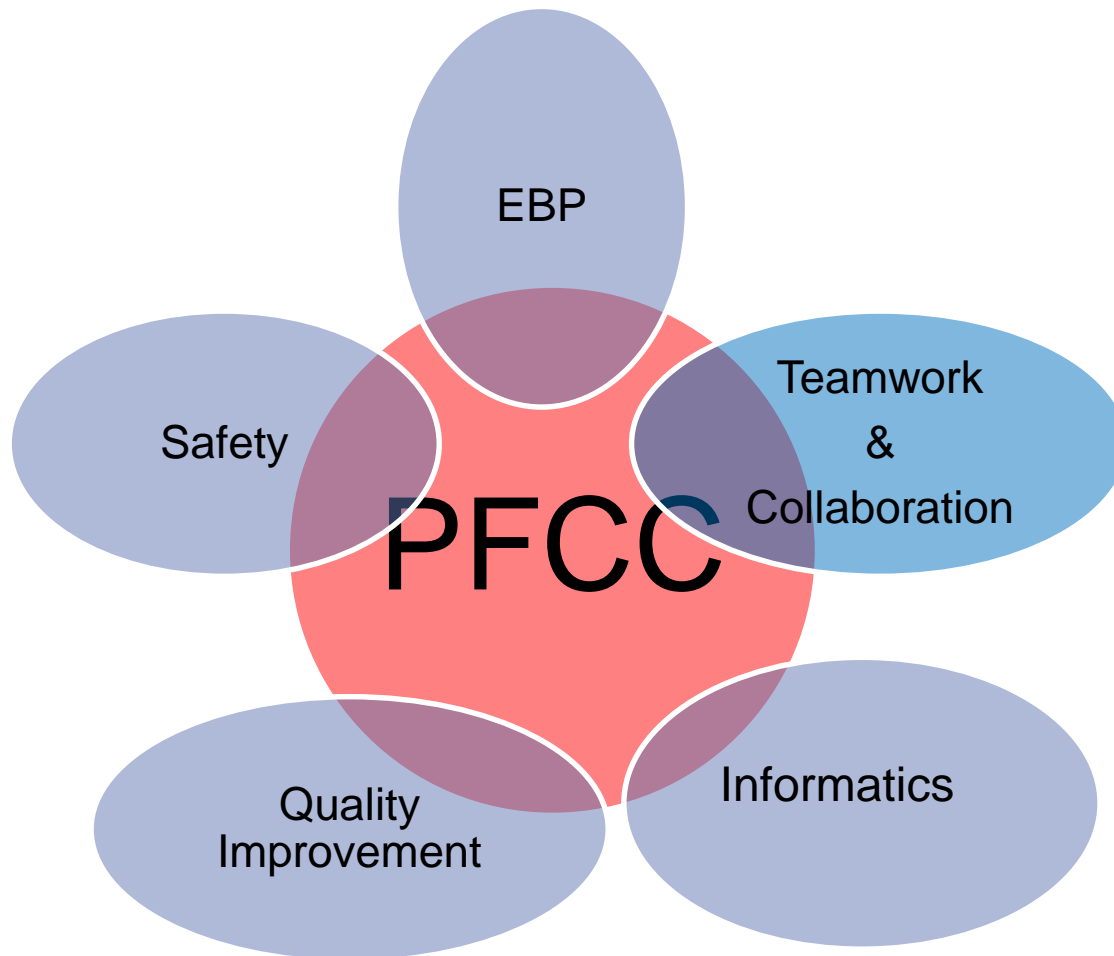


# 5 core principles (IAPO)

- Respect
- Choice and empowerment
- Patient involvement in health policy
- Access and support
- Information



# Institute Of Medicine Competencies



# Why the change in wording?

1. Greater emphasis on wellness and health promotion
2. Many people receiving care aren't in hospitals
3. People with chronic illness don't consider themselves patients
4. Even if someone is in a hospital, we are encouraged to "*engage the person to treat the patient*"
5. Koloroutis and Trout:  
"*See me as a person*"





# Patient power – *person* power



The image is a screenshot of a Forbes article. At the top, the Forbes logo is on the left, and navigation links for "New Posts", "Most Popular", "Lists", and "Video" are on the right. The article is by Dave Chao, a contributor, with a small profile picture and a "Follow" button. The article title is "Patient Engagement is the Blockbuster Drug of the Century". Below the title, there are social media sharing icons for Facebook (45), Twitter (153), LinkedIn (11), and Email (186). The article text begins with "The insight of the year goes to Leonard Kish, a health IT strategy consultant, for making that statement regarding patient engagement. The corollary to this statement is a game changer: What happens when effective patient..."

# International organizations engaged in promoting P&FCC

- World Health Organization Patient Safety initiative
  - Patients for Patient Safety
  - The London Declaration of 2005
  - PFPS Champions (originally 21, now 250 in 50 countries)
- The Pan-American Health Organization
- Institute for Healthcare Improvement
- International Council of Nurses
  
- Gothenburg University Center for Person-Centred Care
- Australian Institute for Patient and Family Centred Care
- Swedish Society of Nursing

# Differences in cultural and social factors

(Disch & Adwan, 2014)

- Who is the family
- What role does the family play? The community?
- Who makes key decisions?
- What is role of men in the society? Of women?
- Who can provide healthcare? To whom?
- What are food preferences? Who can prepare food?
- What are treatment options? Are they available to all?
- What is the meaning of illness?
- What is the family's religion? How influential is it for them?
- Who speaks in important matters?

# Differences (cont)

- What language does the person speak? Is this their predominant language?
- What language is spoken at home?
- What is the concept of time?
- What are the “rules” about healthcare? (e.g., first come/first seen, only the wealthy receive it)
- How is the family and community organized? (e.g., hierarchical, collaborative)

# TAKING CHARGE

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Engaging patients as full partners

# “Nothing About Me Without Me”



Creating partnerships to improve the quality of care

Delbanco, Berwick, Boufford, et al. (2001). Health care in a land called PeoplePower: nothing about me without me. *Health Expectations*, 4(3):144-50.

# Patient & Family Engagement

- Integral - improving quality, safety and patient outcomes
  - Care of Individual
    - Systems and structures to ensure patient values direct care.
      - Planning, assessing, evaluating care *with* patients
      - Admission/goal setting, nurse to nurse handovers, interdisciplinary rounds, care/transition planning meetings
    - Policies & resources to support family members presence and participation
  - Organizational level
    - Patient and Family Advisory Councils
    - Patient participation in quality and safety rounds
    - Staff orientation and professional development programs
    - Advisors involved in strategic planning
    - Environment and design/planning
    - Improvement projects

# Assessment - Organizational Level

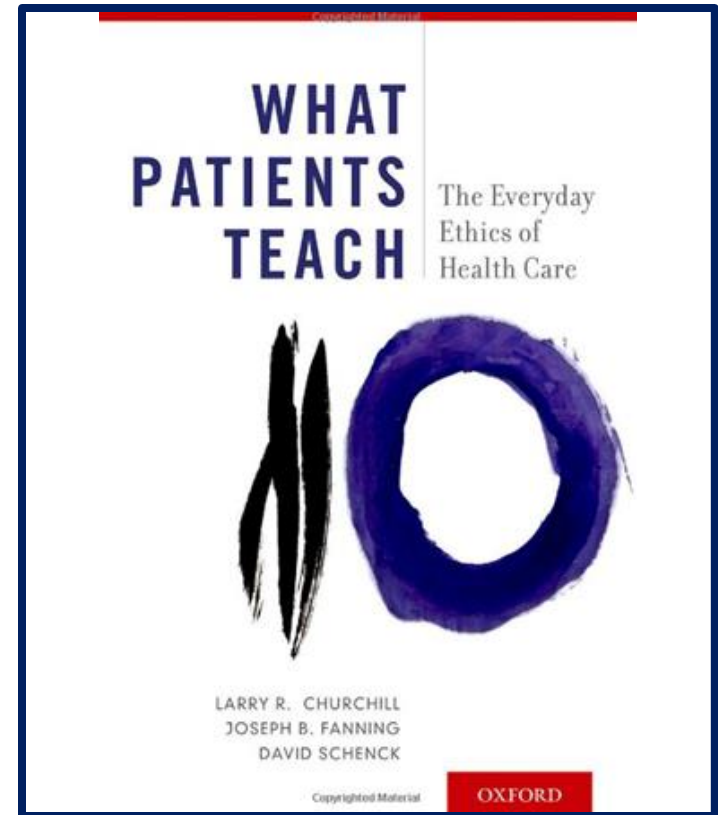
- Leadership/Operations
- Mission, Vision, Values
- Advisors
- Quality Improvement
- Personnel
- Environment & Design
- Information/Education
- Diversity & Disparities
- Charting & Documentation
- Care Support
- Care

Patient- and Family-Centered Care Organizational Self-Assessment Tool						
Elements of Hospital-Based Patient- and Family-Centered Care (PFCC) and Examples of Current Practice with Patient and Family (PF) Partnerships						
Domain	Element	Low	→ High			Do not know
Leadership / Operations	Clear statement of commitment to PFCC and PF partnerships	1	2	3	4	5
	Explicit expectation, accountability, measurement of PFCC	1	2	3	4	5
	PF inclusion in policy, procedure, program, guideline development, Governing Board activities	1	2	3	4	5
Mission, Vision, Values	PFCC included in mission, vision, and/or core values	1	2	3	4	5
	PF-friendly Patient Bill of Rights and Responsibilities	1	2	3	4	5
Advisors	PF serve on hospital committees	1	2	3	4	5
	PF participate in quality and safety rounds	1	2	3	4	5
	Patient and family advisory councils	1	2	3	4	5
Quality Improvement	PF voice informs strategic/operational aims/goals	1	2	3	4	5
	PF active participants on task forces, QI teams	1	2	3	4	5
	PF interviewed as part of walk-rounds	1	2	3	4	5
	PF participate in quality, safety, and risk meetings	1	2	3	4	5
	PF part of team attending IHI, NPSF, and other meetings	1	2	3	4	5
Personnel	Expectation for collaboration with PF in job descriptions and PAS	1	2	3	4	5
	PF participate on interview teams, search committees	1	2	3	4	5
	PF welcome new staff at new employee orientation	1	2	3	4	5
	Staff/physicians prepared for and supported in PFCC practice	1	2	3	4	5
Environment and Design	PF participate fully in all clinical design projects	1	2	3	4	5
	Environment supports patient and family presence and participation as well as interdisciplinary collaboration	1	2	3	4	5



# Care: Individual Level

- Communication training
  - Goal: relationship based care
  - Skill building: listening for understanding; responding to emotions
  - Role play & simulation
- Standard process
  - Engaging patient/family in care activities
  - Patient-directed family participation
- Support for Family Caregivers
  - Ambulatory visits
  - Resources for bedside presence 24/7
  - Caregiver Center



# Improvement: Organizational Level

- Create a culture of engagement
- Recruit patient and family advisors
- Prepare advisors for improvement work
- Implement improvement initiatives and measure impact
- Sustain the relationships over the course of many projects



# Creating Patient and Family Advisor Role

- Leadership support
- Recruit – experience with health system
- Screening –narrative; goals
- Volunteer requirements
- Orientation; ongoing support
- System for project requests
- Engagement in process
- Measure impact



# Story Forums

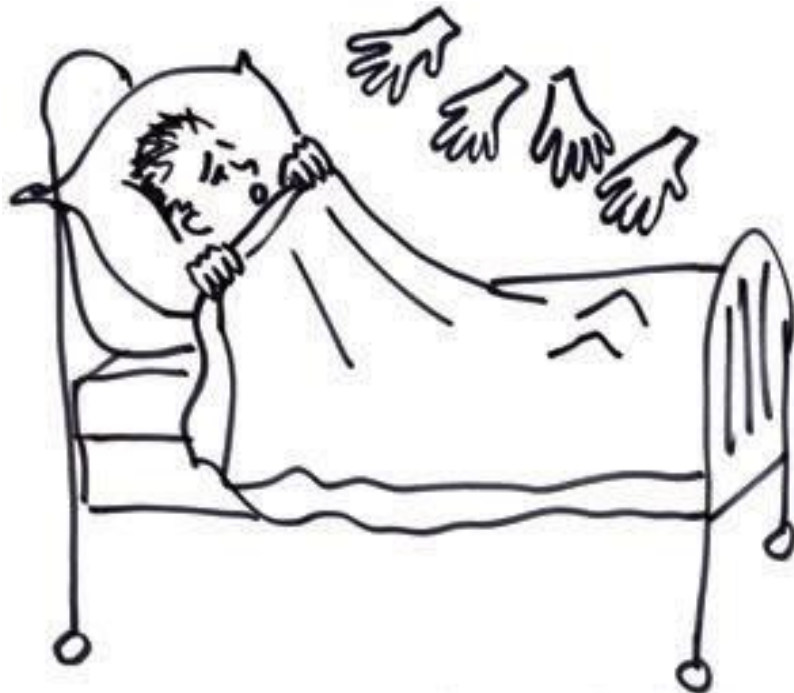


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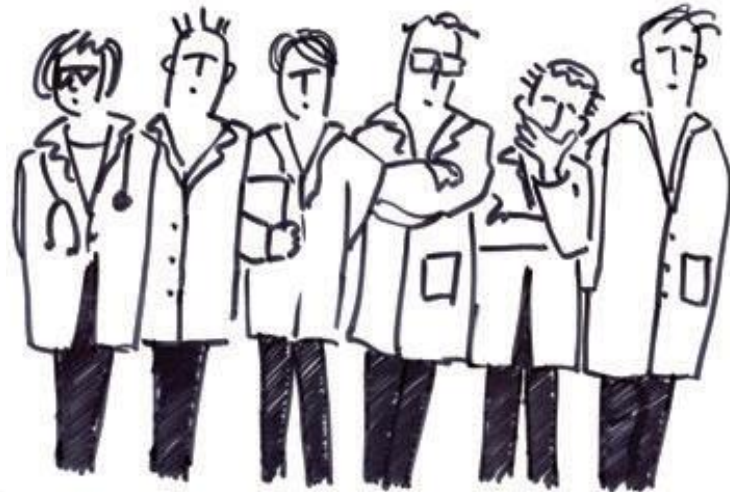
- Health Care Experiences
  - Inform, Inspire
  - Catalyst for change
- Link to organizational goals/needs
  - Preparation – shape narrative to staff/system needs; specific objective
  - Question & Answer time

# Improving Interdisciplinary Rounds

- An ongoing collaboration: unit- based clinical leadership: MD's, RN's, Pharmacy and Quality Staff.



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# Advisors Engagement



Health Research & Educational Trust. (2015, March).  
[www.hpoe.org/pfaengagement](http://www.hpoe.org/pfaengagement)

- Participate in orientation and staff development programs
  - Health System Orientation Video
  - Story forums
    - Nursing Leadership Council
    - Redesign of Unit Secretary Role
    - Environmental Services Staff
  - “Teach Back” Programs
- Quality Improvement Efforts
  - Missing and lost belongings
  - Food Services
- Committees and Task Forces
  - House Staff Quality and Safety Council
  - Infection Prevention and Control
- Research – Patient Centered Outcomes Research
  - Grant proposal input

# Advisors Impact

- Project requests for advisor participation
  - Range of disciplines, departments
- Patient satisfaction scores
  - Therapeutic Nurse-Patient Relationship Initiative
- Program evaluations
  - Professional development
  - Story Forums
- Research proposals



# THE LEADER'S ROLE

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Engaging patients as full partners



# 7 key factors supporting P&FCC at the organizational level

- Leadership
- A strategic vision clearly and constantly communicated
- Involvement of patients and families
- Care for the caregivers through a supportive work environment
- Systematic measurement and feedback
- Quality of the built environment
- Supportive technology

# Evidence of PFCC Outcomes

- Patients more involved in their care are better able to
  - Manage complex chronic conditions
  - Seek appropriate assistance
  - Have reduced lengths of stay; and avoid readmissions and emergency department visits
  - Experience increased patient satisfaction and employee engagement

(Jarousse, 2011):

# Redistributing Responsibility – *Long Island Jewish Hospital, NY*

- 26 year old with Cystic Fibrosis delivered healthy baby



## Redistributing Responsibility – *Long Island Jewish Hospital*

- Developed system for med self-administration
- Patients who opt to self-administer –
  - special locked boxes containing medications.
  - document meds and nurses review
  - nurses and pharmacists keep box filled

## Redistributing Responsibility – *Long Island Jewish Hospital*

- Outcomes
  - Reduced time for delivery of medications for the first breathing treatment for which they were admitted from 15 or more to 2 hours
  - Reduced time for IV antibiotics from 18 to 4 hours
  - Reduced average LOS from 11 days to 7
  - Patient and professional satisfaction surveys- increased from 20% to 95%

# Evidence-Based Benefits of PFCC: Making the Business Case

- 100 Planetree healthcare institutions
  - Increased patient satisfaction
  - Increased staff retention
  - Enhanced staff recruitment
  - Decreased length of stay
  - Decreased emergency department return visits
  - Decreased adverse events including fewer medication errors
  - Reduced operating costs' and a lower cost per case
  - Increased market share
  - Improved liability claims experience

# The leader's role in promoting P&FCC

- Develop the culture – with expectations
- Create the environment
- Implement systems and structures
- Educate everyone including the board and every employee and physician

# What's different?

Traditional	P&FCC
Healthcare provider is the expert	HCP is expert in diagnosis and treatment; P&F are experts in the person's history and experiences
Patient is recipient of care	P&F are partners
One size fits all	Plan and preferences are individualized
Uniformity	Flexibility
Rules and regulations are boundaries	Rules and regs are baselines
Access to information tightly controlled	Free sharing of information with P&F
Decisions are made by administrators, physicians, hospital staff	Decisions are made in collaboration with P&F



# Creating a PFCC Culture

- Balancing organizational missions: education, research, patient care
- Personalizing care
- Overcoming clinician/staff resistance
- Spreading change to all corners of the organization



# Getting started -

1. Educate all senior leaders, staff, patients and families about P&FCC
2. Appoint a steering committee with patients, families, formal and informal leaders
3. Conduct an organizational self-assessment
4. Set priorities and develop action plan



5. Begin to incorporate PFCC concepts into organization's strategic priorities
6. Invite P&F to serve as key advisors in core processes
7. Provide ongoing education and support to P&F and staff
8. Weave stories and examples of P&FCC into board meetings, open forums, communications
9. Monitor changes made, work to continuously improve
10. Celebrate and communicate successes

# Creating supportive environments



# Creating room for families

Evidence shows this can:

- Reduce patient falls
- Reduce patient stress
- Reduce depression
- Improve communication
- Improve social support and satisfaction
- Promote engagement



- “room” can mean different things -



# Lucille-Packard Children's Hospital

family-centered care

FAMILY *to* FAMILY  
S E R I E S

## Family Centered Rounds



Patients and Families  
Join the Team!

**A Guide for Participating  
in Family Centered Rounds**

### You're Invited





Patients and families are now included in Family Centered Rounds.

The ideas, opinions, and questions patients and families bring to the discussion and planning is an important part of the *safe, high quality care* we provide at Packard Children's Hospital.

While we look forward to having you at Rounds, it is not required. It is *your choice to attend*.

**LET US KNOW!** Use the colored magnet on your door to tell us if you'd like to join Family Centered Rounds each day.

 Means "YES" The team will knock on your door when it is time to meet together about your child.

 Means "NO" The team will meet in the hallway and then let you know the plan of care.

When patients are 18 years old, they make the choice about attending Family Centered Rounds.

### What is discussed at Rounds?

The discussion at Rounds will be about *your child's current condition and progress*.

They will talk about:

- ❖ Overnight issues & changes in the last 12-24 hours
- ❖ A "presentation" of health history and current condition
- ❖ New lab and study/test results
- ❖ Daily plan of care
- ❖ Discharge consideration (criteria) and discharge goals for the day



Each team member will share his/her opinion and ideas for your child.

The Attending doctor will make the final decision on the plan of care and will ask if you agree.

### What is the patient and family role at Rounds?

*As a member of the health care team*, you are invited to be an active participant in Rounds.

Patients and families are welcome to:

- ❖ write down questions and notes before and during Rounds
- ❖ listen and add to the medical information presented to the group
- ❖ ask questions to clearly understand the information and decisions being made
- ❖ tell the team what you think will help your child



You decide how comfortable you feel talking during Rounds. Just listening is okay too!



# Myths of PFCC

- Too costly –
  - Actually units less costly, with a shorter length of stay, less cost per stay, and higher patient satisfaction
- Nice but not important
  - Patient- or family-initiated rapid-response teams prevent patient deterioration
  - Medication reconciliation with every person prevents errors
  - Having access to one's own healthcare record can allow persons to correct mistakes





# Myths of PFCC

- Takes more staff –
  - Evidence shows staffing costs are similar
- Only works in small hospitals
  - Depends on the culture, not the size
- Increases infection
  - Studies show no increase in infection with open visiting, pet visitation, children (without URIs)



## Myths to PFCC

- It is a Privacy violation.
  - Access to information is a patient right, and patients can also designate who among their family and friends may also have access to their healthcare information and record.
- Requires renovation or construction.
  - Making physical changes to accommodate persons and family members may increase comfort, but is not required

# Dealing with barriers -

- **INDIVIDUAL**

- Knowledge – studies for past 40 years
- Skill
  - From *caring for patients* to *partnering with them and their families*
- Attitudes
  - “We’re the experts”
  - “We don’t have time”
  - “They’re policing us”

- **ORGANIZATIONAL**

- Changing the traditional model of health care with its bureaucratic structures and practices, historical reward systems and power differentials

It's about creating a culture, not a program

Culture is the way  
you think, act, and  
interact.

# CHANGE THE WORLD OF HEALTH CARE

- Start where you are
- Use what you have
- Do what you can

A. Ashe





# Discussion

