A Trio of Experience: Partnering with Patients and Families for Improvement

Libby Hoy, Founder and CEO, PFCC partners
Joan Forte Scott, MBA, RN, NE-BC, Administrative Director, Patient and Community Engagement, Stanford Health Care
Randall Carter, Senior Vice President, Planetree

Session Objectives

- Identify concrete strategies for co-designing solutions to improve care
- Develop skills to initiate partnerships with patients and families in QI
- Describe techniques to overcome common barriers to creating authentic partnership in the health care environment
We’re honored to be with you

Sharing the Experience of Care
Questions

- Which of the roles did you connect with most closely? Why?
- How did you feel as you experienced the story?
- What went well?
- What was missed? Clinically, Safety and Human Experience?
- Where were the disconnects?

Group Review and Individual Lenses

Many of the truths we cling to depend greatly on our own point of view.
Through the Eyes of
the Patient and Family

Early advocacy efforts challenged the status quo of ‘patients as passive recipients’ of care

“...we should all demand to be treated as competent adults, and take an active part in our healing...we should insist on hospitals meeting our human need for respect, control, warm and supportive care...”

-Angelica Thieriot, 1978
Founder, Planetree

* The 1st patient-centered advocacy organization in the US

Personalize    Humanize    Demystify
“The care of a disease may be entirely impersonal; the care of the patient must be completely personal.”

Francis Peabody, M.D., Care of the Patient, JAMA 1927

Patient-centered care and Patient Engagement are not isolated aims. They are unifying ones, built on human relationships.
What we know..

Patients are our indispensable partners in this effort.

“Patients and their families are essential partners in the effort to improve the quality and safety of health care. Their participation as active members of their own health care team is an essential component of making care safer.”

Dr. Paul McGann and Dennis Wagner, co-directors, National Partnership for Patient
Advocating for what people need

- Compassionate Human Interactions
- Access to Meaningful Information
- Support & Participation of Family, Friends
- Healing Environment
- Support for body, mind & spirit
  - Arts and Entertainment
  - Spirituality
  - Caring Touch
  - Integrative Therapies
  - Healthy Food and Nutrition
- Healthy Communities

Informed by over three decades of focus groups and thousands of voices

The themes that have informed the development of the Planetree methodology for patient-centered care implementation, and the identification of patient-preferred practices, i.e. field-tested practices that respond to how patients, families and staff have expressed they want their care delivered.
“Patient-centered care is not about improving care for patients and families. It is about improving care in partnership with patients and families.”

Patient Directed Visiting

Visitors Welcome

**Patient-Directed Visiting:** the elimination of sweeping restrictions to visiting patients with any limitations imposed on a case-by-case basis and in collaboration with the patient, according to personal preferences and in consideration of their healthcare needs.
Alegent Health Ethnography Project

What was your biggest fear while hospitalized?

Being alone.

Benefits of Patient-Directing Visiting

In a study that examined the benefits of unrestricted patient visitation, 88% of families stated it had a positive benefit to their overall experience and decreased their anxiety by 65%.

Berwick, D, Kotagal, M (2004). —Restricted visiting hours in ICUs: time to change. JAMA, 292: 736-737
Care Partners

Care partner: A family member or friend appointed by the patient who is included as a member of the care team and accepts mutually-agreed upon patient care responsibilities during and between specific episodes of care.

Patient Preferred Practice

centered on you...
At Good Samaritan Hospital, we believe in treating each patient as a whole person—not just a medical condition.

To personalize your healing journey, please share with us the things that bring meaning to your life.

By what name do you like to be called?

Who are the important people in your life?

What gives your life supportive roots?
(e.g. going to church, science/family, meditation)

What are your favorite daily things?
(e.g. hot bath, gourmet coffee, magazine)

What do you do for fun?
(e.g. reading, crafting, going to the movies)

Good Samaritan Hospital

The medical center, centered on you.
The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.

CARE Act goes into effect:

The impact

- Decrease LOS and readmissions.
- Improve communication.
- Improve patient advocacy.
- Improve quality and safety.
- Improve patient satisfaction.
- Improve staff satisfaction.
- Improve patient adherence to treatment plan.
- Decrease medical errors.
“...an estimated **80% of serious medical errors** involve **miscommunication** between caregivers when patients are transferred or handed-off... **communications breakdowns** continue to be a leading contributing factor in many different kinds of sentinel events...”

Joint Commission Online October 21, 2010
Shared medical record: Refers to the patients’ ability to access their real-time, in-progress personal health information during a care episode, e.g. during a hospitalization and/or treatment.

Shared Medical Records

A 2013 survey of 1,000 U.S. patients found*:

• 4 of 5 patients (82%) say being able to access their medical records is important
• 41% would consider switching doctors to gain access to their health records

Accenture Survey on Patient Engagement - Research Recap:
United States, Sept. 2013
Concerns expressed related to patients reading their medical record:

“HIPAA won’t let us do that without a signature and that takes time.”

“What if you’ve written something that offends them? Lawsuit!”

“It’s too complex and I don’t think most of the time they’d understand what was written.”

“I don’t have time to sit down and review the record, and I’m not sure they [the patients] would even want to.”

< 5% of doctors reported longer visits when they opened their notes to patients.

Impact of Shared Medical Record on Overall Patient Satisfaction with Care

Patients who are told they can read their medical chart are more likely to recommend the hospital to others.

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Were you told that you could read your medical chart?
As part of the Planetree Philosophy, patients are encouraged to read their medical record/chart.

Please contact your nurse.
Patients and Families as Partners in Improvement Efforts

Libby Hoy,
PFCCpartners
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Jeopardy Question

What is the most underutilized resource in the healthcare environment for improvement?
PFCCpartners recognizes that the quality of health care outcomes is improved when the expertise of the health care provider is partnered with the experience of the patient and family. From the bedside to boardroom, patient and family centered care is about partnering to design policies, programs, and individual care plans for the best possible outcomes.

Defining the Terms

- Patient (Person) Family Centered Care (PFCC)
  - Noun
- Patient Family Engagement (PFE)
  - Verb
- Patient Experience (PXE)
  - Outcome
What Does Success Look Like?

What Do you Need?

- Patient Family Advisors
- An identified scope of work
- Culture of partnership
- Dedication to the collaborative process
- Structure for partnership
- Context and information
Partners in Improvement

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 authored by the Patient & Family Advisors assembled for the 2012 Institute for Healthcare Improvement Forum, Orlando December 2012

Core Competencies for Patient Family Advisors

- Teachable spirit
- Representative voice
- Solution focused
- Constructive collaboration
- Establish partnerships

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Identified Scope of Work

**Scope**

- Recruitment
- Preparation
- Information
- Focus

Engaging Vulnerable Populations

- Identify your population
- Start a Conversation Interviews
- Create Community Connections
- Expand your team
Culture of Partnership

- Value differing perspectives
- Respectful behavior, tones, language
- Commitment to Collaboration
- Acceptance of Patient Family Experience
- Patient Family Acceptance of Health Care Professional’s area of expertise.

Collaboration

- Common Purpose
- Problem Solving in Development
- Negotiation
- Everyone is Active
Tools of Co Design

- Transparency
- Strength Based Language
- Rules of Engagement
- Commitment to the Team above personal agenda
- Non jargon signs
- Parking lots
- Clear and attainable goals

Active Strategy for Improvement

Strategic Goal
Meet the Standards for Meaningful Use
To generate revenue stream.

Project/Initiative
Design a highly utilized Patient Portal and increase access.

Patient Family Advisor
Co Design the Patient Portal so that it is organized in a way that makes sense to patients and families, with the right information in the right place.
Levels of Patient Family Engagement

- Advocacy
  - Research
  - Legislative Impact
- Shared Decisions
  - Engaged in Care Planning
  - Systems Savvy
- Care Relationship
- Informant
- Policy Change
- Organizational Improvement
- Focus Groups
  - Surveys
  - Interviews
- PFAC
  - Improvement Teams
  - Co Design
- Care Relationship

What is the right structure for engaging PFAs?

Scope
+ Organizational Improvement Pathways

High Impact
Examples of Co Design

Care Relationship: *Trauma Experience*

Hospital/Organizational: *Outpatient LEAN Improvement Event*

Policy/National Level: *National Quality Forum Patient Engagement Action Team*

Exercise Question

- Identify an issue in your work that you would like to solve using a co design approach.
Integrating the Voice of the Patient and Family into the Organization

Joan Forte Scott, MBA, BSN, NE-BC
Administrative Director, Patient and Community Engagement

The Power of Perspective
The Value of Patient and Family Voices

Patients’ and family’s perspectives are **expertise**

Help the organization understand the problem **before** looking for solutions
The Value of Patient and Family Voices

Problem solving *with*, not *for*

The Value of Patient and Family Voices

Challenge assumptions
The Value of Patient and Family Voices

Storytelling is a powerful tool for changing culture

- Open perspectives
- Create empathy
- Change individual behaviors
- Reinforce individual behaviors
- Effect change in the system

The Value of Patient and Family Voices

Keep the team focused and inspired

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The Value of Patient and Family Voices for Staff and Physicians

- “Patient’s voice is an amazing resource.”
- “I am reminded of why I am in health care.”
- “… saved us time in getting to a solution that works.”
  - “Hear when options are needed versus a single solution.”
  - “… heard a completely different perspective.”
  - “… helps me empathize with their struggles.”
- “Patients helped further our objectives.”

The Champions in “The Community”

Video from Institute of Patient Family Centered Care Seminar – hosted by Stanford Health Care

https://stanford.box.com/s/xduv0g9ayziyxpexjlx51
The Value of Patient and Family Voices to the Organization

Patient- and Family-Centered Care Delivers VALUE

- Improved Patient and Family Satisfaction
- Improved Quality, Safety and Clinical Outcomes
- Improved Staff and Physician Engagement

INCREASED REVENUE
- ↑ Market Share
- ↑ Reimbursement
- ↑ Reputation
- ↑ Philanthropy

DECREASED COST
- ↓ Waste
- ↓ Error
- ↓ Utilization

The Power of Patient and Family Voices

Patients and families can contribute materially to outcome improvements because of their knowledge of their illness and the actual experience of care. Patients know what works for them and what doesn’t. They bring another set of eyes, brain, voice and a passion to achieve the same goals we want – remember it is about them.

Jim Conway, Senior VP
Institute for Healthcare Improvement
Stanford’s Patient/Family Partner Program Model - the 360 Perspective

- Manage medical condition
- Manage personal life
- Receive tangible and emotional support

Patient

- Manage patient’s medical condition
- Manage family’s personal life
- Receive tangible and emotional support
- Maintain autonomy

Family

- Meet clinical and regulatory standards
- Manage stressful high-pace work environment
- Work within complex silo’d organization
- Manage emotions in caring for patients/families

Hospital Staff and Physicians

Stanford’s Patient/Family Partner Program

- Patient/Family Advisory Councils (PFACs)
  - Patients, families, staff and physicians partner in dialogues that focus on improving quality

- Patient/Family Speakers
  - Patient/Family Partners teach and motivate by telling personal healthcare stories

- Peer 2 Peer
  - Patient/Family Partners are trained and supporting in providing unique support and understanding of peer-to-peer mentoring, to help foster happier, healthier lives and reduce isolation

- Continuous Improvement
  - Patient/Family Partners are engaged in improvement opportunities in 4 major categories

- Improvement Events
  - Patient/Family Partners participate in half day to multi-day improvement (kaizen) workshops with staff and providers

- Workgroups/Committees
  - Patient/Family Partners consistently participate in key decision-making and design work done outside of improvement events

- Consultations
  - Patient/Family Partners provide consultation and partnership outside of meetings to the leadership of specific initiatives

- Focus Groups
  - Patient/Family Partners provide dialogue and input through one time and periodic meetings
Methods of Engagement

**Focus Groups**

Patient Financial Services

### Advantages
- Relatively quick to implement
- No training needed for PFPs
- Can draw from broad sector
- Staff can observe directly

### Challenges
- Requires skilled facilitator
- Patients/family members are wildcards
- Inexperienced staff want to interact
- No guarantee of attendance
- Hard to measure outcomes—might be mostly attitudinal

### Steps to Implement
- Identify stakeholders
- Define objectives and target PFPs
- Develop questions
- Create invite with RSVP and questions to think about
- Provide training for staff, including preparation for diversity of opinion
- Determine how to record feedback
- Debrief +/- with staff and PFPs
Methods of Engagement

**Workgroups/Committees**

**Advantages**
- Relatively quick—team already exists or is forming
- Clear-cut team leader, usually with leadership skills
- Goals established
- Need only one or two PFPs

**Challenges**
- PFPs are outnumbered and can be intimidated
- Organization’s lingo and acronyms can isolate PFPs
- PFP voice can get lost
- May be run like a staff team, without consideration for PFPs
- Staff often have not been exposed to PFP voice and can be hostile
- Hard to track PFP’s contribution

**Steps to Implement**
- Meet with team lead and executive sponsors to clarify intent and goals
- Select PFPs based on team goals, culture and personalities
- Coach team lead on how to facilitate
- Provide a context for and orient patient/family partners
- Plan for PFP support in meetings—buddies
- Orient workgroup staff to work with PFPs
- Check-in with team lead and PFPs over time
Methods of Engagement
Patient/Family Advisory Councils (PFACs)

In Planning (FY16)
- Geriatrics
- Pain
- Emergency Room
- Lung Transplant
- Primary Care

PFAC Example
Environment of Care
**PFAC Example**

*Delivery of Care*

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**Advantages**
- Create stable, ongoing source of truth
- Promote supportive relationships
- Allow trust to develop between all members
- Develop rhythm of working
- PFPs become chairs—leadership development
- Next meeting is available when new topic needs input
- Vet simple questions—meet staff where they are

**Challenges**
- Time intense
- Time intense
- Time intense

**Steps to Implement**
- Identify leaders and decision makers
- Ascertain authenticity of commitment to voice
- Clarify goals and staff membership
- Create work plan together to assure commitment
- Set expectations
- Identify metrics and outcome measures

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**Methods of Engagement**

*Patient/Family Advisory Councils*
Methods of Engagement

**Improvement Events**

**Advantages**
- Structured
- Led by others
- Organization is invested
- Ideally, staff have voice as well
- Creative environment—out-of-the-box thinking is encouraged
- Problem-focused

**Steps to Implement**
- Meet with executive sponsor to understand their vision
- Meet with event leader to understand their style
- Determine how to track outcomes
- Identify PFP or PFPs
- Orient PFPs to Improvement concepts and practices
- Identify buddy, if PFP is inexperienced
- Debrief +/△ with staff and PFPs

**Challenges**
- Structured
- Led by others
- Difficult schedule for PFPs
- Often only 1 PFP and many staff
- Staff discomfort in hearing PFPs’ perspective
Methods of Engagement

One on One Consultations

Advantages
- Can match partners well—OKC
- Utilize highly skilled PFP
- Can be one-time or ongoing
- Easier scheduling available
- Frequent contact is possible
- Can focus attention on topic(s)

Challenges
- PFP might represent a single voice
- Personalities might not match
- Staff must be highly motivated
- May be unable to track concrete outcomes

Steps to Implement
- Meet with staff to understand their needs
- Scope the project with staff—be specific
- Identify the appropriate consultant
- Facilitate the first meeting
- Conduct periodic check-ins with both staff and PFP partners
- Debrief +/- with staff and PFP
Exercise Questions

Considering the problem you identified before break,

1. How would you bring the opportunity to co-design on this issue into your organization?

2. Describe why you chose the method (i.e., What is it’s unique value to the initiative?)

3. What structures already exist that allow you to add different perspectives to problem-solving?

Changing Culture

Put the patient at the center—at the absolute center of your system of care. Put the patient at the center for everything you do. In its most helpful and authentic form, this rule is bold; it is subversive. It feels very risky to both professionals and managers, especially at first. It is not focus groups or surveys or token representation. It is the active presence of patients, families and communities in the design, management, assessment and improvement of care itself.

*Dr. Donald Berwick, National Health Service*
Bringing it all together

Thinking and Learning Together
Next Steps

What Will Your Verse Be…?
Thank You!

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