Engaging Patients, Families and Communities to Improve Health and Healthcare Systems

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Mountain Pacific Quality Conference, Casper, Wyoming
Reinvent the healthcare industry so that hospitals, healthcare organizations and stakeholders continuously partner with empowered patients and families as a resource in the co-design of programs, policies, and quality improvement activities.
Partner with healthcare organizations and the public to provide a collaborative learning community where the sharing of proven methods, successes, and challenges will guide the development of sustainable Patient Family engagement structures across the healthcare continuum.
Team Hoy

A story of partnership impacting the health and well-being of a family living with chronic illness
Emotional Response

- Guilt
- Denial
- Loss
- Confusion
- Isolated
- Overwhelmed
- Angry
- Helpless
- Fear
Ready for Engagement

calm

confident

comfortable
Definitions

• Patient (Person) Family Centered Care (PFCC)  
  **Noun**

• Patient Family Engagement (PFE)  
  **Verb**

• Patient Experience (PXE), Quality Improvement, Safety Improvement  
  **Outcome**
Ingredients of Partnership

- Respect
- Choice
- Strength Based
- Individualized
- Expressed Compassion

- Flexibility
- Collaboration
- Empowerment
- Quality Communication

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Engagement **NOT** Entitlement
Engagement = Empowerment

David Emerald’s TED* (*The Empowerment Dynamic) triangle provides an alternative to the Karpman Drama Triangle

- Creator
- Challenger
- Persecutor
- Coach
- Rescuer
- Victim

TED*
- Passion-Based
- Outcome-Focused

Dreaded Drama Triangle
(Karpman’s Drama Triangle)

Anxiety-Based
Problem-Focused

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Outcomes in the making…
Jeopardy Question

What is the most underutilized resource in the healthcare environment for improvement?
Engaging Patients & Families

Clinical Relationship

Organizational Improvement
Levels of Patient Family Engagement

Shared Decisions Engaged in Care Planning Systems Savvy

Care Relationship

Informant

Policy Change

Organizational Improvement

PFAC Improvement Teams Co Design

Advocacy Research Legislative Impact

Focus Groups Surveys Interviews

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Quality  Safety  Facilities
Program  Design  Patient  Experience  Policy
Active Strategy for Improvement

Strategic Goal
Reduce Readmissions

Project/Initiative
Implement a community coalition of stakeholders including Advisors to design a transition program.

Patient Family Advisor
Informs the work from the patient perspective, pointing out challenges and/or gaps specific to that community.
Collaboration

Common Purpose

Problem Solving in Development

Negotiation

Everyone remains active
Patient Family Advisors

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

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Co Design

- Clinicians
- Patients & Families
- Health Care Organizations
# National Drivers

<table>
<thead>
<tr>
<th>Organization</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Academy of Medicine</td>
<td>• Scientific Advisory Panel</td>
</tr>
<tr>
<td></td>
<td>• Patient Family Advisory Leadership Network</td>
</tr>
<tr>
<td>National Quality Forum</td>
<td>• Integrating Patient Family Advisors onto Action Teams</td>
</tr>
<tr>
<td></td>
<td>• Actively Learning engagement</td>
</tr>
<tr>
<td>Institute for Healthcare Improvement</td>
<td>• PFCC Team</td>
</tr>
<tr>
<td></td>
<td>• Bringing Patients &amp; Families in for Co Learning</td>
</tr>
<tr>
<td>CMS Innovation Center</td>
<td>• Patient Family Engagement Affinity Group</td>
</tr>
<tr>
<td></td>
<td>• Actively Learning Engagement</td>
</tr>
<tr>
<td>American College of Physicians</td>
<td>• Patient Partnerships Advisory Board</td>
</tr>
<tr>
<td></td>
<td>• Establishing standards for their Membership</td>
</tr>
</tbody>
</table>
Center for Medicare Medicaid Services (CMS)

**TCPI**  
Transforming Clinical Practice Initiative

**Pfp**  
Partnership for Patients

**QIO**  
Quality Improvement Organization

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Engaging Vulnerable Populations

- Identify your population
- Start a Conversation
- Interviews
- Create Community Connections
- Expand your team
“All this is so different for healthcare providers. It’s like a great restaurant learning that their new business is going to be – in addition to continuing to provide a great in-restaurant experience – teaching people how to cook at home. What? This isn’t what we do! It’s impossible!”

Leonard Kish,
Forbes Magazine
September 9, 2012
The Challenge of Engaging

Who wants change?

Who wants to change?
New & Unchartered Territory!
Force Field Analysis

Positive Driving Forces
positive forces for change

Restraining Forces
obstacles to change

Engaging Patients & Families in Improvement
Success Stories
What Would it Look Like if Patients & Families were engaged from the bedside to the boardroom?
Let’s get started!!!
Elements of PFCC Integration

Executive Support
- Philosophical
- Financial
- Programmatic

PFCC Leadership
- Interdisciplinary Team
- Campus Wide Representation
- Identified in Strategic Plan

PFA Engagement
- PFAC
- PFAs on Committees
- Established Opportunities for Patient Family Input

Impact on Practice
- Physician Education
- Staff Education
- New Hire Orientation

Organizational Improvement
- PFAs integrated into improvement structure

Environment
- Culture
- Facility Design
- Signage
- Culturally Competent
Patient Family Advisor

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.
Gateways to Engagement Learning Collaborative®

Set the Table

Recruitment

Orientation

Launch Meeting

Sustainability Practices
Keys to Success

- Active Leadership Commitment
- Strong Vision
- Interdisciplinary Team
- Identified Scope
- Preparation
The Case to Leadership

Patient Family Engagement = Strategy for meeting organizational goals

Quality  Safety  Experience
### Vision Template

<table>
<thead>
<tr>
<th>Scope</th>
<th>Who are you serving? Hospital Impact?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategic Plan</td>
<td>What parts of the strategic goals are targeted for Patient Family Engagement? Could be broad/inclusive or targeted.</td>
</tr>
<tr>
<td>Motivation</td>
<td>Why now? What is going on specific to your organization at this time that makes this the time to implement patient family engagement.</td>
</tr>
<tr>
<td>Patient Family Advisors</td>
<td>What is the role? How will they impact our hospital? What characteristics will your hospital value in Patient Family partnerships?</td>
</tr>
</tbody>
</table>
Implementation

Patient Family Advisory Councils

- Integrated Approach to Improvement
- Organizational Commitment

Rapid Improvement Teams

- Interdisciplinary Teams
- Area of Experience

Focus Groups

- Single Focus
- Starting point

Starting point
Interdisciplinary TEAMwork!

- Facilitator -
- Leadership Representative
- Communications
- Project Managers
- Administrative Support
Preparation

Advisors
- Context
- Relevance
- Expectations

Staff
- Vision
- Anticipated Contributions
- Expectations
Orientation of Patient Family Advisors
Core Competencies

- teachable spirit
- representative voice
- solution focused
- constructive collaboration
- establish partnerships
I was able to practice new skills with peers in the training setting through scenario based learning and receive immediate feedback. Every advisor needs this class!

Michelle, PFA

I’ll look at things differently now. I will be more diligent to understand the other perspectives. I didn’t realize I wasn’t doing that!

Carol, PFA
Ingredients of Partnership

- Respect
- Choice
- Strength Based
- Individualized
- Expressed Compassion

- Flexibility
- Collaboration
- Empowerment
- Quality Communication
Points of Engagement

- Program Design
- Facilities Design
- Advocacy Efforts
- Foundation Efforts
- Marketing Efforts
- Staff Appreciation Efforts
- Story Telling
- Organizational Board
- E-Advisors

- Patient & Family Advisory Councils
- Quality Initiatives
- Safety Initiatives
- Committee participation
- Family Faculty presentations
- Peer support
- Document review
- Staff interviews

Starting points
Requires some experience
Requires More Experience and/or additional training
### Solution Focused

#### Shared Challenges

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Patient /Family</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Space Restraints</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>HIPAA</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Restricted Access</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Fear of Harm</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Guilt</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Feeling in the Way</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Families lack of Understanding</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Competing Priorities</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Unfamiliar Environment</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Consistent Communication</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Language Barriers</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Action Planning

STOP

Continue

START
Resources

American College of Physicians
https://www.acponline.org/practice-resources/patient-care-resources-and-tools

PFCCpartners
www.pfccpartners.com

IHI Principles for Radical Redesign
http://www.ihi.org/resources/Pages/Publications/10NewRulesAccelerateHealthcareRedesign.aspx

American Institute of Research, RoadMap to PFE
http://patientfamilyengagement.org/

Institute for Patient Family Centered Care (IPFCC)
www.ipfcc.org