Enriching Outcomes through Patient Engagements: Tools to Use

Sara Guastello
Director of Knowledge Management
Planetree

MaryBeth Kurland, CAE
Chief Executive Officer
Commission for Case Manager Certification
Agenda

• Welcome and Introductions

• Learning Objectives

• Presentation:
  • MaryBeth Kurland, CCMC
  • Sara Guastello, Planetree

• Question and Answer Session
Audience Notes

• There is no call-in number for today’s event. Audio is by streaming only. Please use your computer speakers, or you may prefer to use headphones. There is a troubleshooting guide in the tab to the left of your screen. Please refresh your screen if slides don’t appear to advance.

• Please use the “chat” feature below the slides to ask questions throughout the presentations. We will pose questions after the presentation and will address as many as time permits.

• A recording of today’s session will be posted within one week to the Commission’s website, www.ccmcertification.org

• One continuing education credit is available for today’s webinar only to those who registered in advance and are participating today.
After the webinar, participants will be able to:

1. Identify the role of patients and families in engagement and the foundational principles of participatory engagement;

2. Discuss the benefits for patients and their caregivers when they gain access to their own records and become engaged in their ongoing care; and

3. Describe three ways case managers can invite engagement from patients and family members.
Enriching Outcomes through Patient Engagements: Tools to Use

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“...partnering with persons and families is a critical factor in achieving improvements in the quality and safety of care.”

--Strategic Vision Roadmap for Person and Family Engagement (PFE), Centers for Medicare & Medicaid Services, January 2016
How Healthcare Orgs Can Drive Family Engagement in Patient Care

Family engagement is key for providing emotional and logistical support during patient-centered care.
Introduction

Sara Guastello
Director of Knowledge Management
Planetree
Enriching Outcomes through Patient Engagement: Tools to Use

September 27, 2017

Sara Guastello
Director of Knowledge Management
Goals for Today

1. Identify the role of patients and families in engagement and the foundational principles of participatory engagement.

2. Discuss the benefits for patients and their caregivers when they gain access to their own records and become engaged in their ongoing care.

3. Identify three ways case managers can invite engagement from patients and family members.
What will it take to create a healthcare culture of patient and family engagement?
Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care

Susan B. Frampton, Ph.D., Planetree; Sara Guastello, Planetree; Libby Hoy, PFCCpartners; Mary Naylor, Ph.D., F.A.A.N., R.N., University of Pennsylvania School of Nursing; Sue Sheridan, M.B.A., M.I.M., D.H.L., Patient-Centered Outcomes Research Institute; Michelle Johnston-Fleece, M.P.H., National Academy of Medicine

January 2017

ABSTRACT | Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in partnership with patients and their families (as defined by the patient) in a way that integrates their preferences, values, and desired health outcomes. This vision represents a shift in the role patients and families play in their own care teams, as well as in ongoing quality improvement efforts.
Reflections on Evolving Definitions

2001: Patient centered care is providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.*

2017: Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes explicit and partnered determination of goals and care options, and it requires ongoing assessment of the care match with patient goals.**

*Institute of Medicine, Crossing the Quality Chasm, 2001
**National Academy of Medicine & Planetree, Harnessing Evidence and Experience to Change Culture, 2017
“...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 USA
DEVELOPING THE FRAMEWORK
NAM Goals:

- Better care
- Better evidence
- Better value

Care Culture & Decision-making Innovation Collaborative

Patient & Family Leadership Network

- Scientific Advisory Panel on the Evidence Base for Patient and Family Engaged Care
Goals for the Project

- Support the National Academy of Medicine’s aim to help facilitate the advancement of patient and family engaged care (PFEC) by building and disseminating the evidence-base for the tools, strategies, and culture required.

- Develop a common understanding of elements essential for creating and sustaining patient and family engaged care culture in healthcare settings.

- Identify the scientific evidence-base supporting these elements.

The Scientific Evidence-Base for a Patient and Family Engaged Care Culture
Goal: Identify research and researchers who can contribute to the evidence-base for this work...

- Jim Atty, Waverly Health Center
- Bruce J. Avolio, PhD, University of Washington
- Michael Barry, MD, Healthwise; Professor of Medicine, part-time, Harvard Medical School
- Julie Béliveau, MBA, DBA, Université de Sherbrooke
- Sheila Bosch, PhD, LEED AP, EDAC, University of Florida
- Eric A. Coleman, MD, MPH, University of Colorado, Denver
- Susan Frampton, PhD, Planetree -- CHAIR
- Dominick Frosch, PhD, Palo Alto Medical Foundation Research Institute
- Sara Guastello, Planetree
- Jill Harrison, PhD, Planetree
- Judith Hibbard, DrPH, University of Oregon
- Mohammadreza Hojat, PhD, Thomas Jefferson University
- Libby Hoy, PFCCpartners
- Harlan M. Krumholz, MD, SM, Yale University
- Laura McClelland, PhD, Virginia Commonwealth University
- Mary Naylor, PhD, FAAN, RN, University of Pennsylvania School of Nursing
- David P. Rakel, MD, University of New Mexico
- Helen Riess, MD, Harvard Medical School, Mass. General Hospital; Chief Scientist, Empathetics Inc.
- Ann-Marie Rosland, MD, MS, University of Michigan Medical School and Research Scientist, VA Center for Clinical Management Research
- Joel Seligman, Northern Westchester Hospital
- Sue Sheridan, MBA, MIM, DHL, PCORI
- Jean-Yves Simard, Université de Montréal
- Tim Smith, MPH, Sharp Memorial Hospital
- Susan Stone, PhD RN NEA-BC, Sharp Coronado Hospital
- Carol Wahl, RN, MSN, MBA, CHI Health Good Samaritan
Goal: Develop a common understanding of essential elements for creating and sustaining a patient and family-engaged culture.
Questions for Scientific Advisors

COMMON ELEMENTS
What common elements emerged from these case studies as important drivers for creating and sustaining a culture of PFCC and meaningful engagement?

CONNECTIONS TO YOUR RESEARCH
Reflect on your own research. How do these case studies align with your understanding of culture change and PFCC?

• How do these case studies support what you’ve found in your research?

• Based on your research, what key pieces were missing from these case studies?

EVIDENCE GAPS
What other research should inform a more comprehensive, evidence-based definition of PFCC?
What emerged: **Guiding Framework for Patient & Family Engaged Care**

**Leadership**
- Commitment to change
- Leadership vision and behaviors aligned with PFEC
- PFEC as strategic priority

**Lever for Change**
- Assessment of current state
- Change champions
- Industry, business, policy and payer incentives for PFEC

**Structures**
- Shared governance
- Promoting transparency, visibility & inclusion among personnel and patients/families in design, improvement, and research activities
- Interdisciplinary and cross-sector teams
- PFEC-aligned personnel management practices
- Built environment that facilitates PFEC

**Skills and Awareness Building**
- Training to expand partnership capabilities of healthcare personnel and patients/families
- Development, sharing, translation of research

**Connections**
- Connection of skill-building for personnel and patients/families
- Experiential learning
- Connection to purpose

**Practices**
- Promoting patient and family engagement
- Attending to the emotional, social and spiritual needs of patients/families and personnel
- Engaging patients/families in research activities

**Better Engagement**
- Patient/family activation
- Increased family presence
- Increased feelings of autonomy
- Reciprocal relationships

**Better Decisions**
- Improved health confidence
- Improved decision quality

**Better Processes**
- Improved care coordination
- Culture of safety

**Better Experience**
- Improved sleep
- Reduced stress
- Improved communication
- Decreased grievances and malpractice claims

**Better Health**
- Improved patient-defined outcomes
- Increased patient self-management
- Improved quality of life
- Reduced illness burden

**Lower Costs**
- Appropriate utilization and length of stay
- Improved efficiency
- Appropriate spending
- Better value for patients and families

**Better Culture**
- Joy in practice
- Inclusive culture
- Increased compassion
- Improved experiences
- Improved staff retention
- Reduced burnout/stress

**Better Care**
- Care plans match patient goals
- Improved symptom management
- Improved safety
- Improved transitions
- Decreased readmissions
- Reduced disparities

**Better Experience**
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Highest Level: Transformational Stages
Core Elements with Each Stage

MONITORING

DATA COLLECTION

ORGANIZATIONAL FOUNDATIONS

Leadership

Levers for Change

STRATEGIC INPUTS

Structures

Skill & Awareness Building

Practices

Connections

PRACTICE OUTPUTS

Better Engagement

Better Decisions

Better Experience

Better Processes

ENGAGEMENT OUTCOMES

Better Culture

Better Care

Lower Costs

Better Health

INCREASING CO-CREATION

CONTINUOUS FEEDBACK
# Implementation Clarity & Direction

## Leadership
- Commitment to change
- Leadership vision and behaviors aligned with PFEC
- PFEC as strategic priority

## Levers for Change
- Assessment of current state
- Change champions
- Industry, business, policy and payer incentives for PFEC

## Structures
- Shared governance
- Promoting transparency, visibility & inclusion among personnel and patients/families in design, improvement, and research activities
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## Lower Costs
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- Improved efficiency
- Appropriate spending
- Better value for patients and families
## Engagement Practices

**Practices**

- Promoting patient and family engagement
- Attending to the emotional, social and spiritual needs of patients/families and personnel
- Engaging patients/families in research activities

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<thead>
<tr>
<th>Care Partners</th>
<th>Shared Medical Record</th>
<th>Collaborative Goals</th>
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<td><img src="image" alt="Care Partners" /></td>
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[@planetreesara](#)  
[www.planetree.org](#)
Show Me the Evidence!
Goal: Identify the scientific evidence base supporting PFEC

Bibliography

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## APPENDIX B: Patient and Family Engaged Care: A Guiding Framework – Bibliography of Associated Evidence

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<td>Improved (patient-defined) health outcomes</td>
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What research tells us about the impact of involvement of the patient’s family

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<th>Better Engagement</th>
<th>Engagement of hospitalized patient’s family in care activities and care coordination – a ‘Care Partner’ program - improved patient outcomes, including</th>
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From Knowledge to Action: Care Partner Program

• Family formally engaged as integral member of care team
• A partnership between family and staff
• Provides a source of continuity
• Prepares loved one for post-discharge

“They showed my husband how to do my dressing changes so I don’t have to come here every day. They asked him questions: Can you see it? Do you understand? For him to see, he was very informed.”
Shared Medical Record/Open Notes

**Better Engagement**
- Patient/family activation

**Better Experience**
- Improved communication
- Decreased grievances and malpractice claims

**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.

Practices

- Promoting patient and family engagement
The evidence in support of **shared medical records**

77% of patients who reviewed their doctors’ notes report feeling more in control of their care.

- **Patients who are told they can read their medical chart are more likely to recommend the hospital to others.**
- **Definitely would recommend this hospital to others**

\[\text{Yes} \quad \text{No}\]

Went you told that you could read your medical chart

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

*Delbanco, T. et. al. 2012, Annals of Internal Medicine*

@planetreesara www.planetree.or
From Knowledge to Action: A Shared Medical Record Policy

- Access to **real-time** information **at the point of care**.
- **Maximizes patients’ access** to their personal health information, with limitations to full access the exception to the rule.
- Provisions for how patients will be **supported in understanding** the record.
- Protects **confidentiality** by establishing processes by which the patient controls who is able to access the record.
- Provides avenues for patients to correct inaccuracies and/or omissions, as well as to **contribute** progress notes.
3 Ways Case Managers Can Invite Patient/Family Engagement

1. Ask patients to identify a care partner.

2. Ask patients what matters most to them when setting goals.

3. Apply Teach Back & Reflective Listening to ensure you and the patient are on the same page.
What to learn more?
Plain Language – Share with your colleagues and your patients!

An Invitation to Engage

Dear Patients & Families,

Recently, there has been a lot of discussion about how to make healthcare better for everyone. This includes patients, families, healthcare staff, and the lay organizations and agencies that organize, provide, and pay for healthcare. Research strongly suggests that we can improve peoples’ health; their healthcare experience, and help healthcare staff enjoy their work more by involving patients and family members as equal partners in the process. That is, healthcare can only be improved if everyone works together. For many years, healthcare providers tried to make things better without asking patients and families what they thought or what mattered to them.

That way of doing things is changing.

The new way of doing things is called ‘Patient and Family Engaged Care’.

Whatever you call it, the basic idea is that healthcare professionals need to partner with patients and families to ensure that your care matches your values, preferences, and goals. The means that you need to have conversations with healthcare providers about what health means to you, what you value, what you like, what your goals are for your health, and what you need them in order to live your healthiest life.

This idea of ‘Patient and Family Engaged Care’ has become so important that the National Academy of Medicine recently asked a group of experts, called a scientific advisory panel, to collect and summarize the research evidence that demonstrates what a positive difference this approach makes. The good thing is that the information is now gathered all in one, easy-to-find place. It is called a “Framework for Patient and Family Engaged Care” and can be found here.

The purpose of this document is to invite YOU patients and family members, to engage in your healthcare. We have developed a list of suggestions for you to use in the ‘real world’ to make sure that patient and family engaged care happens every time you go to the doctor’s office, hospital, nursing home, or other healthcare setting.

Being an engaged member of your healthcare team can mean different things to different people. Some people will be more comfortable being engaged than others; it may feel different than what you are used to. The good news is that research shows that patient and family engaged care leads to better relationships between you and your healthcare provider. It helps keep patients safe. It reduces healthcare costs and keeps people from being unnecessarily admitted to the hospital. Patient and family engaged care makes healthcare staff feel more connected to the work they do which makes for a better experience for everyone. The best way to see the benefits of patient and family engaged care is to try it for yourself. We’ve created a ‘To-do list’ of suggestions for patients and family members on the next page. Try one or try them all. You are an expert about you, and an important member of your healthcare team. We invite you to engage with us in making healthcare better for everyone.

LEARN MORE AT WWW.PLANETREE.ORG

Harnessing the Evidence for Patient and Family Engaged Care

What is Patient and family engaged care (PFEC)?

Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in active partnership with patients and their families. (Or care partners as defined by the patient) to ensure integration of their health and healthcare goals, preferences, and values. It includes explicit and partner determined goals and care options, and it requires ongoing assessment of the care match with patient goals.

Recently, the National Academy of Medicine asked a scientific advisory panel of experts to collect and summarize the evidence for patient and family engaged care (PFEC). As a result, a publication paper is now publicly available with all of the information to support PFEC in one place (https://www.nationalacademies.org). The paper includes a framework for PFEC, which describes specific changes and steps that healthcare organizations need for PFEC to truly flourish in process and practice. The purpose of this document is to summarize the 38 page paper for busy healthcare professionals.

Until now, patient and family-centered care (PFCC) has focused on changing patients’ behaviors—patients are seen as the “problem” to be fixed. PFEC recognizes that healthcare leaders have to drive a “patient-centered culture of care that continuously integrates patient and family perspectives and involvement—at the point of care—in health care system design, and in delivering outcomes that matter most.”

Here’s a quick summary of what we know about PFEC & Why it Works:

- We know what organizations have to do to make it work. It means creating a different culture in healthcare organizations. The research shows that to do this, you have to develop a workplace where all staff members share the same feelings and values about the importance of partnering with patients in everything related to their healthcare. This influences day-to-day behaviors in the workplace and bigger policy and practice decisions.
- PFEC starts at the top of the organization. To make it happen, leaders need to be committed and transparent.
- It takes time. It requires the support of leadership to build open governance, to have people work in teams, to buy skills and encourage communication among and between staff and patients.
- It depends on everyone, at every level. It requires training for everyone to build skills in empathy, listening, and respect.
- It requires communication in all directions. There have to be systems of continuous feedback from patients to providers and decision-makers to ensure that changes make a good difference. Patients have to be really encouraged to participate, and told how they make a difference.
- PFEC leads to better outcomes and experiences for patients and families.
- Healthcare staff are happier when patients and families are engaged with them.
- One lesson for all of us is that every concern and complaint is an opportunity. An opportunity to problem solve, improve, grow, and develop better relationships.
- There is more to learn.


http://planetree.org/invitation-to-engage-for-patients-and-families/
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<tr>
<th>Date</th>
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<tr>
<td>4/05/2017</td>
<td>Shared Medical Record Primer</td>
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<td>Patient-Directed Visitation Primer</td>
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<td>Patient and Family Partnerships Councils and Beyond Primer</td>
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<td>Care Partners Primer</td>
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<td>Bedside Shift Report Primer</td>
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Sara Guastello, Director of Knowledge Management
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Question & Answer Session

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Thank you!

- Please fill out the survey after today’s session.
- Those who signed up for continuing education will receive an evaluation from the Commission.
- A recording of today’s webinar and slides will be available in one week at http://ccmcertification.org

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