Objectives

Participants will be able to:

- Describe the benefits of involving patients and families as partners
- Recognize the valuable role of family caregivers in high quality care transitions
- Share tips on getting patients and family members involved and removing barriers to effective partnerships
- Use a self-assessment tool on readiness for patient engagement
Qualitative Studies

What do persons and their families have to teach us about their experiences during care transitions?
Information Transfer

“They overmedicated me like you wouldn’t believe [in the NH]. All they had to do was make one call to my primary care doctor”

- Poor inter-professional and inter-institutional communication
The doctor did not know that there was no way my wife could take care of me

Family and caregiver needs often overlooked or expectations for care provision unrealistic

© Eric A. Coleman, MD, MPH
Self-Management

“A lot of times the questions don’t come until you get home”

- Often did not know the questions to ask or the person to direct them to

© Eric A. Coleman, MD, MPH
Empowerment

“You know, we’re responsible for our own healthcare and it’s our fault if we fall through the cracks”

- Contribution to care plan not taken seriously
- Need for an advocate

© Eric A. Coleman, MD, MPH
Adding More Care Managers Won’t Fix It!
Case Managers Do Not Perform The Majority of Care Coordination...
Supporting Family Caregivers:
United Hospital Fund of New York

Next Step in Care provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.

Transitions are moves between care settings, for example, hospital to home or rehab facility, or the start or end of home care agency services. Because transitions are often rushed, miscommunication and errors can occur.

Next Step in Care materials emphasize careful planning, clear communication, and ongoing care coordination.

In the Media
Andrea Chalupa's Huffington Post blog explores family caregiver stress as a factor in the recent JetBlue flight attendant meltdown—featuring an essay by Carol Levine and a Post-Journal column about health care-related websites prominently features the Next Step in Care, calling it a "wonderful resource.

New Guide on Hospice and Palliative Care
The newest addition to the website is Family Caregiver's Guide to Hospice and Palliative Care, available in English, Spanish, Chinese, and Russian, and designed to help family caregivers understand their options at a difficult time in

http://www.nextstepincare.org/Caregiver_Home/
Activation Is Developmental

Level 1: Starting to take a role
Patients do not yet grasp that they must play an active role in their own health. They are disposed to being passive recipients of care.

Level 2: Building knowledge and confidence
Patients lack the basic health-related facts or have not connected these facts into larger understanding of their health or recommended health regimen.

Level 3: Taking action
 Patients have the key facts and are beginning to take action but may lack confidence and the skill to support their behaviors.

Level 4: Maintaining behaviors
Patients have adopted new behaviors but may not be able to maintain them in the face of stress or health crises.

Increasing Level of Activation

(c) Judith Hibbard, PhD University of Oregon
Literacy vs. Patient Activation

- For most of the behaviors, activation plays an equal or larger role than literacy.
- Taking on and maintaining new behaviors requires self-efficacy as well as knowledge.
- Taking on new behaviors also requires a belief that this is one’s “job” to manage health.
- Where information is the primary requirement (e.g. making Medicare choices), literacy plays a larger role.

Judith Hibbard, PhD University of Oregon
Your Turn

Share with the large group:

Local examples?

Thoughts?

Surprises?

Questions?
Provocation from Don Berwick

“Are patients and their families… someone to whom we provide care?

Or,

Are they active partners in managing and redesigning their care?”

- Donald Berwick, M.D. Plenty, 2002 IHI Forum Plenary
Three Levels of Engagement

Patients and family caregivers:

1. Participate in shared decision making and care processes
2. Participate in giving feedback and ideas on improvement or participate at the project level
3. Are partners in improving, design, or redesign of care delivery processes or infrastructure
The Patient Engagement Evolution

“Doing **to** patients

![Up arrow] Doing **for** patients

![Up arrow] Doing **with** patients

![Up arrow] Doing **with** patients and their families”

“It’s a profound paradigm shift.”

Barbara Balik, *Common Fire*, 2011
Table Exercise

Share at your tables:

1. Your examples of engaging patients and families in improvement
2. Are your examples “To”, “For”, or “With”? 

Share with the large group an example of partnering with patients
“Start before you are ready!”

Jim Anderson
Chairman of the Board
Cincinnati Children’s Hospital and Medical Center
Patient and Family Advisory Council: St. Luke’s Hospital Heart Care Services

Purpose:
“Dedicated to St Luke’s mission ‘Give the health care we’d like our loved ones to receive’ and to supporting the principles and practice of family-centered care.”

Provide input on:
- Enhancing patient and family experience of care
- On delivery of services for patients and families that support or enhance family-centered care
St. Luke’s Hospital: Critical Care/ Heart Care Services

Provide input and feedback on:
- Educational programs, classes, written materials, and home visits
- Program development
- Facility design or renovation

Participate in:
- Education/orientation of hospital associates
- Annual review of accomplishments and goal setting
- Recruiting new members
Patients as Partners

INTEGRATED PRIMARY ACUTE AND COMMUNITY CARE

IPCC Integration Leadership Committee (ILC)

IPCC Patients as Partners (PasP)
Provincial Steering Committee

IAP2’s Public Participation Spectrum

1500 Trained Patient Partners

Inform Consult Involve Collaborate Empower

Increasing Level of Public Impact
Toni Cordell

Patient who did not understand found her voice

- Local and national health literacy advocate
  - Workshop co-presenter
  - Patient partner in health literacy programs
  - Faculty in medical residency programs
  - Keynote speaker

Turning stumbling blocks into stepping stones: www.tonicordell.com/
Assessing Readiness and Depth of Patient Engagement
## A Multidimensional Framework for Patient and Family Engagement in Health and Health Care

### Continuum of Engagement

<table>
<thead>
<tr>
<th>Levels of engagement</th>
<th>Consultation</th>
<th>Involvement</th>
<th>Partnership and shared leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Direct care</strong></td>
<td>Patients receive information about a diagnosis</td>
<td>Patients are asked about their preferences in treatment plan</td>
<td>Treatment decisions are made based on patients' preferences, medical evidence, and clinical judgment</td>
</tr>
<tr>
<td><strong>Organizational design and governance</strong></td>
<td>Organization surveys patients about their care experiences</td>
<td>Hospital involves patients as advisers or advisory council members</td>
<td>Patients co-lead hospital safety and quality improvement committees</td>
</tr>
<tr>
<td><strong>Policy making</strong></td>
<td>Public agency conducts focus groups with patients to ask opinions about a health care issue</td>
<td>Patients' recommendations about research priorities are used by public agency to make funding decisions</td>
<td>Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs</td>
</tr>
</tbody>
</table>

### Factors influencing engagement:
- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)

The Guide to Patient and Family Engagement in Hospital Quality and Safety:

Engaging Patients and Families to Improve the Quality and Safety of Care We Provide

Information to Help Hospitals Get Started;

- How to select, implement, and evaluate the Guide’s strategies
- How patient and family engagement can benefit your hospital
- How senior hospital leadership can promote patient and family engagement

PFAC Toolkit

Detailed Toolkit to:
- Engage patients
- Develop Advisory Councils

Available at the Colorado Hospital Association

Patient and Family Engagement Survey

American Hospital Association

HRET

Health Research & Educational Trust
In Partnership with AHA

Gordon and Betty Moore Foundation

PATIENT AND FAMILY ENGAGEMENT SURVEY
Fostering Patient and Family Engagement: Does the Hospital…

1. Have a patient/family advisory committee?
2. Do bedside rounds and include patients and families?
3. Have a person who involves patients in safety design?
4. Have a board member that received care and/or experienced harm in the hospital?
5. Offer a planning checklist given to patients in the ED?
Key Findings

- Few hospitals have implemented majority of Patient & Family Engagement strategies (room for improvement)
- Strategies occur at multiple levels:
  - Direct care
  - Organizational design and governance
  - Policy making
- Embracing these strategies => improved HCAHPS scores


AHA/HRET Survey Supported by the Gordon and Betty Moore Foundation
More Information on Partnering with Patients and Families


