



“Start before you are ready!”

**Accelerating Change: Engaging Patients
and Families in Redesign**

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These presenters have nothing to disclose.

Session Objectives

Participants will be able to:

- Describe the benefits of involving patients and families as partners.
- 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.

The Patient's Voice



Toni Cordell

The Patient's Voice



Norma Kenoyer
Adult Learner, Iowa

“Challenges associated
with everyday tasks...”

Most Important Component

- Your own belief and conviction
 - Is patient or family care giver participation essential?
- Yet . . . without this experience, how could you be certain?
- To increase your degree of belief if lacking experience: Who can you talk to who has done this? When have you been “like a patient; a family member - can we walk in their shoes?”

Your Turn

- Tell us about your experience with engaging patients and families, e.g.
 - Patient & Family Advisory Councils
 - Serving on teams or projects
 - Serving on improvement committees
 - Partnering in care processes

Selecting Patients and Family Members for your team

- Who interacts well with many different kinds of people?
- Speaks comfortably and with candor?
- Appropriately assertive?
- Compliments a weakness on the team?
- Works without hierarchy?
- It doesn't have to be fair, just needs to work

Key Characteristics of the Patient or Family Representative:

- Good communication skills
- Comfortable working collaboratively with diverse individuals in a group setting
- Representative of patients -including cultural or ethnic communities
- A stakeholder in transitions home

Select Someone Who...

- You know well enough
- Can give insights on things you don't know
- Shares insights about personal experiences in ways that others can learn from them
- Sees beyond personal experiences
- Shows concern for more than one issue
- Listens well and respect others' perspectives

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Tips for Recruitment

- Ask your providers for recommendations
 - Include 2 so they can cover for each other, one may fall ill and to prevent marginalization
 - More than one encourages speaking up
- What patients or family members do you know from readmissions who fit the bill?
- When team lead makes the recruitment call - cover the details role, meeting frequency, where, when, dial in?

Be Candid with New Team Members

- Mission and goals of the project
- Expectations for their participation
- Meeting times and frequency
- Travel dates
- Time commitment beyond meeting times
- Compensation offered or mileage, baby sitting?
- Training and support provided

At their first meeting, orient!

- How meetings will be run: any group process norms about participation (round robin, what to do when you disagree, politeness, etc.)
- Reminders of time, place, frequency. Identify and overcome logistical barriers (transportation, babysitting availability, etc.)
- What you need from patient or family caregiver member

Tips for meetings

- Help with language:
 - Review unique language, jargon
 - Try a “jargon card” for flagging jargon
 - Create a “lingo” translation guide
- Review team specific AIM, results, changes
- Storytelling (trust building exercises) for team building and ice breakers
- Hold regular meetings

Confidentiality Statement

- The confidentiality statement should meet requirements for HIPAA compliance
- Confidentiality statement possibly the same as hospital volunteers
- Compliance Officer should review the confidentiality statement
- Consider whether patient team member should join the hospital volunteer auxiliary for HIPAA compliance or other supports

Patient and family members' advice

Patient and family caregiver team members recommend that you

- Spend more time orienting patients to:
 - The organization
 - The improvement team
 - Why patient involvement is important
- Have more than one family/patient member

Start before you are ready!

Jim Anderson
Chairman of the Board
Cincinnati Children's Hospital and Medical Center

St. Luke's Hospital - Critical Care/ Heart Care Patient Care Services

Purpose:

- The Patient and Family Advisory Council (FAC) at St. Luke's Hospital Heart Care Services is dedicated to helping the service fulfill its mission "To give the health care we'd like our loved ones to receive" and to support the principles and practice of family-centered care

St. Luke's Hospital - Critical Care/ Heart Care Patient Care Services

Functions:

- Provide input/feedback to improve or enhance patient and family experience, i.e., customer satisfaction
- Provide input and feedback on delivery of services for patients and families that support or enhance family-centered care
- Provide input and feedback on facility design or renovation

St. Luke's Hospital - Critical Care/ Heart Care Patient Care Services

Functions: (cont.)

- Provide input and feedback on educational programs, classes, written materials, home visits, etc.
- Provide input regarding program development

St. Luke's Hospital - Critical Care/ Heart Care Patient Care Services

Functions: (cont.)

- Participate in education/orientation of hospital associates
- Annually review accomplishments and set goals
- Assist in recruiting new members

Partnering with Patients and Families Readiness Assessment

Name of Organization/Team: _____



Area	Current Experience: make a mark (an X, a circle, or anything that is easy to read) in the box that best describes your team or organization's experience.		
Data transparency	We have not discussed the possibility of sharing performance data with patients and family members.	Our team is comfortable with sharing improvement data with patients and families related to current improvement project.	This organization has experience with sharing performance data with patients and families.
Flexibility around aims & specific changes of improvement project	We have limited ability to refine the project's aims or planned changes.	We have some flexibility to refine the project's aims and the planned changes.	We are open to changing both the aims and specific changes that we test based on patient and family team members' perspective.
Underlying fears and concerns	We have not discussed our concerns about involving patient and families on improvement teams.	We have identified several concerns related to involving patients and families on improvement teams but have no plan for how to address or manage them.	We have a plan to manage and/or mitigate issues that may arise due to patient and family member involvement on our team.

Partnering with Patients and Families

Readiness Assessment

Perceived value and purpose of patient/family involvement	There is no clear agreement that patient and family involvement on improvement teams is necessary to achieve our current improvement aim.	A few of us believe patient and family involvement would be beneficial to our improvement work, but there is not universal consensus.	There is clear recognition that patient and family involvement is critical to achieving our current improvement aim.
Senior leadership support for patient and family involvement	Senior leadership do not consider pf involvement a top priority.	Senior leaders are aware of and communicate support for pf involvement in our team.	Senior leaders consider our participation in this Web & Action as a pilot for organizational spread.
Experience with patient and family involvement	Beyond patient satisfaction surveys or focus groups our organization does not have a formal method for patient/family feedback.	We have an active patient/family advisory panel.	Patient and families are members of standing committees and make decisions at the program and policy level.
Collaboration and teamwork	Staff in this organization occasionally works in multidisciplinary teams to provide care.	Staff in this organization work effectively across disciplines to provide care to patients.	Patients and family are included as valued members of the care team in this organization.
<ol style="list-style-type: none"> 1. What supports moving in this direction? 2. What are your current challenges? 3. How confident are you on successfully involving patients and families on your team (1-10 scale)? 			

Questions?