Creating a Patient and Family Advisory Council

Presented By:
Institute for Patient- and Family-Centered Care

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Resources

- Application Form for Patient and Family Advisors
- Checklist for Attitudes about Patients and Families as Advisors
- Creating Patient and Family Advisory Councils
- Definition of an Advisor
- Orientation for Patient and Family Advisors: Topics to Include
- Patients and Families as Advisors: Broadening our Vision
- Presentations by Patients and Families: Staff Liaison Coordination and Preparation Roles
- Sharing Your Story: Tips for Patients and Families
- Tips for How To Be an Effective Patient and Family Advisor: A Beginning List
- Tips for Recruiting Patient and Families to Serve in Advisory Roles

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Key Topics We Will Discuss Today

- Advisory/Partnership – similar or different?
- Focus groups, advisory groups, work groups
- Examples of accomplishments – hospitals, clinics, home care
- Staff roles
- Advisors
  - Recruiting
  - Key qualities
  - Orienting/Preparing
- Council Structure – meetings, bylaws, officers
- Getting Started
- Lessons Learned
- Resources
Creating Advisory/Partnership Councils

Learning about the patient’s and family’s experience...

Focus groups and surveys are not enough!

Hospitals, health systems, ambulatory programs, primary care practices, behavioral health services, long-term care communities and other community-based agencies must create a variety of ways for patients and families to serve as advisors.

What it is….

Focus group?
An advisory council?
Collaborative committee?
Workgroup?

Partners in Care Council
“Nurturing an Ideal Care Experience”

Focus Groups

- Usually 8 to 10 participants
- Ad hoc group or team
  - Resolving a given problem within a larger group
  - Identifying the spread of opinions and feelings on the issue
  - Does not resolve issues
  - Does not make decisions or policy
  - Discuss an existing, planned product, service or process
Work Group or Process Improvement Team

- Size dependent on representation needed
- Formed around a specific issue or topic
  - Discuss an existing, planned product, service or process
  - Collaborate on finding a solution
  - Not a formalized council
  - Group is not ongoing – when the issue is solved, the group stops meeting
  - Do make decisions or policy or recommend to higher level body

Collaborative or Partnership Council – the “next generation” advisory council

- Empowered to find solutions
- Staff and patient/family partners collaborate on decisions
- Partnership Council
  - Opinions are not perceived as merely advisory
  - Staff may bring issues looking for advice
  - Formalized, long-term, defined memberships

Advisory Councils

- Empowered to advise
- Offer guidance; a group providing expert information
  - Informal
  - Short-term
- Advisory Council
  - Opinions may be perceived as merely advisory
  - Should be empowered to be more than advisory
  - Formalized, long-term, defined memberships

Advisory or Partnership Councils

- Vary in size, form, structure, and name
- Purpose is the same:
  To serve as a formal mechanism for involving patients and families in policy and program decision making in health care settings.
Mental Barriers

- We don’t have time for this.
- Patients will hear the negatives about our organization.
- We don’t want to air our dirty laundry.
- This is nice to talk about, but…
- Patients/families just don’t understand our system.
- They will want things that cost too much and we’ll have to tell them “no.”
- We are not a hotel; we are here to save lives.
- We need to be better organized.

Blanchfield Army Community Hospital
Patient & Family Advisory Council
Fort Campbell, KY

- Assisted in planning Patient and Family Resource Center
- Conducted site visits to established centers with staff and physician

Clear your mind of “can’t”.

Making Changes and Improvement with Patient and Family Advisors — Memorial Health System, Hollywood, FL

- Patient and family advisors have been involved with staff in the development and design of . . .
  - The Patient/Family Resource Center
  - Signage and Wayfinding
  - ICU Family Waiting Area Computer Stations
  - Family-initiated Rapid Response Alert process
  - “E-Health” Team Website re-design
  - Trauma Team Family-Witnessed Resuscitation Protocols
  - Daily Med Administration Reconciliation form
  - Palliative Care Patient/Family Education
Patient and Family Advisory Council - Multiple Sclerosis Clinic MCG Health System, Inc. Augusta, GA

Projects in Partnerships: Advisory Councils Make a Difference

Can Advisory Councils really have an impact?

- Medication Safety
- Patient Satisfaction
- Doc Talk Form
- Communication (white boards)
- Renovation Projects
- Billing
- Family Guide to Services

What it is not...

a support group!

Recruiting Patient and Family Advisors
Staff Liaison/Recruitment Coordinator

- Initial Questionnaire
- Interview Process
- Expectations
- Matching Skills and Interests

Recruitment

- Ask patients/families during a clinic visit or during a hospital stay when appropriate.
- Ask staff and physicians for suggestions.
- Contact support groups.
- Call or send a mailing to patients and families.

Recruitment

- Post signs/brochures on bulletin boards in waiting areas
- Place notices in:
  - Clinics’ and hospitals’ - publications and websites
- Direct Email Recruiting
- Twitter, Facebook
- Technology – hospital or clinic TV, information kiosks

Resources

[Image of Institute for Patient- and Family-Centered Care]

TIPS FOR RECRUITING PATIENTS AND FAMILIES TO SERVE IN ADVISORY ROLES

- Ask other patients and families who are already involved if they have a friend who might be interested in participating.
- Ask providers to identify patients and families.
- Contact patient or family networks, support groups, or advocacy organizations.
- Post notices in appropriate languages on bulletin boards in reception areas in clinics and in hospital emergency rooms.
- Post notices in appropriate languages on bulletin boards at educational, recreational, and social service programs, clinical services, and families.
CREATING PATIENT AND FAMILY ADVISORY COUNCILS—GETTING STARTED

Bremerton Naval Hospital
Bremerton, WA

University of Washington Medical Center
Seattle, WA

Recruitment Brochure
Team Up for Health (TUFH) is a multi-year initiative funded by the California HealthCare Foundation to advance the practice of self-management support in ambulatory clinics through communications training, practice redesign, and meaningful partnerships with patient and family advisors.
Patient and Family Advisors – Set for Success

Successful Patient and Family Advisors

- See the “big” picture
- Share personal experiences in ways that others can learn from them
- Interested in more than one agenda item

Successful Patient and Family Advisors

- The ability to listen and hear other points of view
- Represent patient population
- A sense of humor
- The ability to connect with people

What if – not a good fit...

- Review skills and attributes
- Is there another advisory role
- Keep name on a list
- Be clear and honest
- Example letters
Fostering a Successful Beginning: Beginning Patient and Family Advisors

- Use Volunteer Department or Red Cross Volunteer Program
  - Background checks
  - Health Assessment
  - Portion of Orientation
  - Maintain Volunteer Advisor Hours
  - Recognition Efforts
  - Annual Compliance for Joint Commission

Fostering a Successful Beginning: Orienting Patient and Family Advisors

- Mission, Values, Priorities of the Unit, Clinic or Hospital
- Speaking the Language – Medical Jargon 101
- Who’s Who in the Organization

Fostering a Successful Beginning: Orienting Patient and Family Advisors

- Meeting Attendance Expectations
- Safety-Security Protocols
- Infection Control
- Hospital/Clinic Tour
- “Day in the Life”

Fostering a Successful Beginning: Orienting Patient and Family Advisors

- Logistical Details
  - What to wear
  - Where to find food and drink
  - Location of bathrooms
  - Transportation and parking
  - Child care
  - Stipends/Reimbursements
Fostering a Successful Beginning: Orienting Patient and Family Advisors

- Roles and Responsibilities on the Council
  - Patients, Families, Staff

- Confidentiality and Privacy
  - HIPAA Training
  - Signing Confidentiality Statement

Fostering a Successful Beginning: How to be an effective advisor

- How to ask questions
- What to do when there is a disagreement
- Listening and learning from other’s viewpoints
- Thinking beyond your own experience
- Sharing your story
- Telling “negative” stories in a positive way
- The impact of anger

Fostering a Successful Beginning: Raising Difficult Issues

- Set ground rules for discussion.
- Set stage for open, honest, frank discussions.
- Share own experiences.

Fostering a Successful Beginning: Keep emotions even

- Rules of good communication
  - Listen carefully.
  - Clarify what is being said.
  - Only one speaks at a time.
  - Someone needs to facilitate.
Fostering a Successful Beginning: Orienting Staff

- Serve as a connection between other staff and the advisory group
  - Assist in communicating activities of the advisory group to other staff
- Be a patient- and family-centered “champion”

Fostering a Successful Beginning: Orienting Staff

- Respond to issues in their respective areas based on what they hear from the advisory group.
- Provide information for the advisory group.

Fostering a Successful Beginning: Orienting Staff

- Explain how staff should be involved.
  - The importance of listening
- Be open to questions and challenges.
- Try not to be defensive.
  - Respond/explain without being defensive
  - Defensiveness usually has a negative effect

Creating Advisory Groups
Use of a “Workgroup” or PIT or QIT

- Provides an informal way to try a new way of collaborating.
- Helps staff become comfortable having patients and family members at the table.
- Identify a clear goal or purpose.
- May be built around a particular topic or theme.

Use of a “Workgroup”

- Define how the group will be structured.
- Identify resources that are needed.
- Identify a link with senior leadership.
- Publicize activities.
- Allow leaders to emerge.

Development around Specific Activities

Perham, MN – new nursing home and hospital

Nursing home – something is different here
New Hospital opened
January 9, 2012

Perham Living, Perham, MN
Patients involved in new hospital
Perham, MN

- Went on site visits
- Signage – continue to be involved
- Actual move day
- Patient/family areas
- Resource center – being developed
- Greeters at entrance
- Furniture choices

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Perham, MN
“Walk of Honor”

- Started in nursing home
- Treating death with dignity
- Involving family as they wish
- Another activity on the healing journey
- Council
  - Book of prayers, sayings
  - Made quilt for walk

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Creating a Council or Multiple Councils

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Different Types of Councils

- Patient
- Parent and family
- Adolescent and children
- Residents in long-term care communities
- Hospital
- Clinical services
- Support services
- Ambulatory clinics
- Home care/VNS
- Health plans

Humboldt Open Door Clinic
Patient Advisory Board - August 2010
Different Types of Councils

- Coordinating Council
  - Or
  - Steering Comm.
  - (Reports to Quality Committee or Leadership Team)

- Orthopedics Council
- Ambulatory Council
- Oncology Council

Youth Advisory Council - IWK Grace
Halifax, Nova Scotia

- “Soft Tissue for Sore Bones”
  - Safety – preventing skin breakage and infection
  - Dignity – preventing embarrassing sore “bums”

- Engaged
  - Director of Maintenance – could systems handle soft tissues
  - Director of Engineers
  - VP of Patient Care
  - Purchasing
  - MDs and Managers
Youth Advisory Council
IWK Grace, Halifax, Nova Scotia

Bottom line
- Slogan – “Having fun with Purpose”
- Passionate about TP
- Keep softer toilet tissue in supplies for teens with Crohns

Council Structure

Size
- 12 – 30

Composition
- Reflection constituencies/member diversity

Terms of Membership
- Staggered terms

Terms of Membership
- Staggered terms
- 12 members
  - 3 – one year terms
  - 3 – two year terms
  - 3 – three year terms

Can reapply for designated number of terms.
Council Structure

- **Officers**
  - Staggered terms

- **Chair or Co-Chairs**
  - Establishes agenda
  - Leads meetings

- **Secretary**
  - Takes minutes
  - Distributes meeting notices

Should staff be members in the role of patient or family advisors?

Council Structure

- **Staff participation - 2-3 or more patient and family members to 1 staff**

- **Identify a staff liaison**

- **Include senior leadership**

- **Encourage other staff to attend as guests**

Meetings

- **Logistics**
  - Meeting times – convenient to staff and patients/family members
  - Length - 2 hours
  - Frequency – monthly
  - Place – accessible, adequate space
  - Refreshments?
Meetings

- Importance of introductions
- Agendas must not be too long
- Allow time for discussion

Meetings

- Acronym free zone
- Assure everyone is heard
- Team building activities
- Patient- and family-centered care education

Structure – Things to Think About

- Bylaws/guiding principles
- Sub-committees
- Compensation and reimbursement
  - Childcare and transportation

Appreciation

- Honorariums
- Training/Learning opportunities
- Gift cards
- Cards/E-Cards
Patient and Family Advisory Councils – How to Get Started

Getting Started or Restarting

- Adequate time for introductions
- Brainstorm – “one change”
- Assure everyone is heard
- Multi-voting to choose 2-3 priorities

Getting Started or Restarting

- Review and redo annually
- Start with a “fun” project – easily accomplishable
- Track accomplishments – annual report
- Celebrate successes

Team Up for Health

Northeast Valley Health Corporation — Celebrating and Recruiting Advisors — Invitations sent to patients who had made dramatic improvement in A1c levels
Cambridge Health Alliance  
Boston, MA

Celebrating and Thanking Patient and Family Advisors

This organization, serving the immigrant gateway communities near Boston, holds a Thanksgiving turkey dinner with all the trimmings to celebrate and thank patient and family advisors.

Effective Patient and Family Partnerships - Lessons Learned

- It takes time to develop comfort and confidence with working in a new way and to achieve measurable results.
- Orientation and preparation of staff, physicians, patients, and families are essential.
- Advisors can be trained to be effective advisors.

Effective Patient and Family Partnerships - Lessons Learned

- Patient advisors are practical and focus on what doesn’t work.
- Small changes have BIG effects.
- Can’t delegate patient- and family-centered care - accountability.
- Leaders have to be involved and visible.
- Recognize successes.
- Track outcomes; submit monthly/annual report to senior leaders.

Resources

Institute for Patient- and Family-Centered Care website resources:

www.ipfcc.org

Click on Tools for Change and then Downloads
Click on Advancing the Practice and then Patients and Families as Advisors and Leaders
Resources

A PATIENT AND FAMILY ADVISORY COUNCIL WORKPLAN: GETTING STARTED

A. Initial Steps for Starting a Council
1. Stakeholders: helps define the purpose of your advisory council and get support and/or commitment.
   a. Physicians
      - Name
      - Role
      - Contact Info
   b. Nurses
      - Name
      - Role
      - Contact Info

Resources

Google: Patient Advisory Councils or Family Advisory Councils

Children’s Hospitals and Clinics of Minnesota
http://www.childrensmn.org/Communities/FamilyAdvisoryCouncil.asp

Resources

Patient and Family Advisory Council Network (PFACnetwork):
http://mailman.listserv.com/listmanager/listinfo/pfacnetwork

Patient and Family Advisors and Leaders of Advisory Councils for Hospitals
This listserv is for anyone interested in the work of patient and family advisory councils.

Resources

Cincinnati Children’s Hospital
http://www.cincinnatichildrens.org/about/fcc/family/default.htm

Dana-Farber Cancer Institute
http://www.dana-farber.org/pat/pfac/advisory/default.html
http://www.dana-farber.org/pat/pfac/adult-advisory/default.html
Changing the Culture of an Organization . . .

A Journey, Not a Destination
IPFCC Webinars

- Advanced Session: Sustaining and Enhancing a Patient- and Family-Advisory Council
- Applying Patient- and Family-Centered Concepts and Strategies to the Development of the Medical Home and the Management of Chronic Conditions
- Applying Patient- and Family-Centered Concepts in Dealing with Challenging Situations with Patients and Families
- Changing the View that Families are Visitors—Strategies that Support Family Presence in Newborn Intensive Care and Pediatric Settings
- Collaborating with Youth and Families to Create Successful Transitions to Adult Health Care
- Creating Patient and Family Advisory Councils—Getting Started
- Developing Patient- and Family-Centered Peer Support Programs
- Enhancing Patient- and Family-Centered Communication at the Bedside and Beyond
- Enhancing the Collaborative Process: Preparing, Supporting, and Mentoring Staff and Patient and Family Advisors to Advance Patient- and Family-Centered Care
- Exploring the Role of Leaders in Patient- and Family-Centered Care
- Hospitals and Communities Advancing Patient- and Family- Centered Care: A Beginner’s Guide
- Implementing a Patient and Family Faculty Program to Strengthen a Patient and Family-Centered Culture
- Patient and Family Involvement in Change of Shift Report
- Patient and Family-Centered Care in Adult ICU’s
- Patient- and Family-Centered Approaches in Transitions from NICU/PICU to Home
- Patient- and Family-Centered Care in Adult ICU’s
- The Road Less Traveled: Integrating Pediatric Palliative Care and Patient- and Family-Centered Care
- The SMART Discharge—An ‘Always’ Event
- Through Their Eyes: Collaborating with Patients and Families from Hospital Design through Moving In

www.ipfcc.org/events/webinars.html