Patient and Family Advisory Council

Getting Started Tool Kit

Created by Meghan West and Laurie Brown Skunks Team
A TOOL KIT FOR CREATING A PATIENT AND FAMILY ADVISORY COUNCIL

STEP BY STEP GUIDE FOR CREATING A PATIENT AND FAMILY ADVISORY COUNCIL

CREATED BY MEGHAN WEST AND LAURIE BROWN SKUNKS TEAM
ACKNOWLEDGEMENTS

Thank you to the Family Advisory Council at Children’s Hospital. They were the first Advisory council within BJC. They provided a vision for involvement of families in all aspects of patient care.

Thank you to Missouri Baptist Cancer Care Center, Christian Hospital Cancer Care Center and Barnes-Jewish St. Peter’s Hospital Siteman Cancer Center for being the first to start on this journey toward working together with our patients and families.

We also want to thank the patients and families we have met along the way. We continue to be inspired by your passion to deal with chronic illness WHILE partnering with our healthcare staff to make a difference.
In 2007, our boss, Ginny Clark, presented her vision to our team of starting Patient and Family Advisory Councils (PFAC) at the BJC community hospitals. So like any good, loyal staff, we rolled up our sleeves and got to work. During the next several months we embarked on a journey that truly energized us and motivated us to want to come to work each day, ready to change the healthcare experience WITH our patients and family members. Our journey started with research, what we call PFAC preparedness – site visits, interviews, and the development of a methodology that served as our guide for how to establish a PFAC. Two hospital cancer centers volunteered to trial our PFAC methodology – Missouri Baptist Medical Center Cancer Center and Christian Hospital Cancer Care Center. Experiencing this process has changed our lives and the lives of the hospital staff, patients, and family members involved. This book is the culmination of all that we learned along the way. It is our hope that others may use it and improve upon it in order to create a culture in the healthcare environment where PFACs are viewed as an integral part of how decisions are made.

A Patient and Family Advisory Council (PFAC) partners patients and families with members of the healthcare team to provide guidance on how to improve the patient and family experience. As part of this PFAC process, patients and families are invited to serve on hospital committees to ensure that the consumer’s point of view, perspective, and experience are not only heard, but also integrated into the service and quality improvements that are engineered to ensure high-quality, customer-centered care. Through their unique perspectives, they give input on issues that impact care, ensuring that the next patient or family member’s journey is easier.
**BENEFITS OF A PATIENT AND FAMILY ADVISORY COUNCIL**

For the Healthcare Organizations:
- Provide an effective mechanism for receiving and responding to consumer input.
- Result in more efficient planning to ensure that services really meet consumer needs and priorities.
- Lead to increased understanding and cooperation between patients, families and staff.
- Promote respectful, effective partnerships between patients, families and clinicians.
- Transform the culture toward patient-centered care.
- Develop programs and policies that are relevant to patient’s and families’ needs.
- Strengthen community relations.
- Recognize that collaboration with their providers through patient-centered care leads to better self-management of chronic conditions and improved adherence to medication regimens.

For Patients and Families:
- Gain a better understanding of the healthcare system.
- Appreciate being listened to and having their opinions valued.
- Become advocates for the patient and family-centered healthcare in their community.
- Understand how to become an active participant in their own healthcare.
- Develop close relationships with other members on the council.
- Provide an opportunity to learn new skills (facilitating groups, listening skills, telling their story).

**UNDERSTANDING POSSIBLE BARRIERS**

Attitudinal Barriers:
- Fear that patients’ and families’ suggestions will be unreasonable.
- Fear that patients and families will compromise confidentiality.
- Belief that a customer service program is sufficient to ensure patient satisfaction.
- Lack of imperial evidence supporting patient and family involvement in decision-making.
- Belief that patient and family-centered care is not necessary (“we know what is best for our patients”)
- Belief that patient and family-centered care is time-consuming and requires additional staffing.

Organizational Barriers:
- Lack of guiding vision.
- Tendency to implement either a top-down approach to initiating partnerships with insufficient effort put in to building staff commitment, or a tendency to implement a grass roots effort that lacks leadership, commitment and support.
- Organizational culture.
- Scarce resources and competing priorities.
- Inadequate organizational leadership.
Are you ready to partner with your patients and family members? Creating a patient and family advisory council is a great first step. The voice of our patients and family members can be a powerful tool in improving safety, patient satisfaction and quality. By forming a patient and family advisory council you and your team are starting a new journey of truly embracing patient and family-centered care. Like any new idea, the concept may sound “fun”, but actual implementation can be challenging. That is why there must be a well thought out engagement/acceptance plan for this journey.

Advisory Council Guiding Principles:

- Patient and family-centered care applies to patients of all ages.
- PFACs may be established in any healthcare setting.
- Family is defined in its broadest scope; anyone who is close to the patient and provides support is considered as family.

Patient and Family-Centered Care Guiding Principles:

1) **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

2) **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

3) **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

4) **Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation; in facility design; and in professional education, as well as in the delivery of care.
**Patient and Family Advisory Council Sponsor**
- Should be a leader of the organization.
- Helps to motivate and guide the PFAC effort.
- Advocates to educate staff/leadership about the advisory council.
- Helps to recruit staff, patients and families to roles in the planning committee, steering committee and council.
- Attends weekly planning committee meetings.
- Attends monthly PFAC meetings.

  - **Time commitment:**
    - Preparation/Planning Phase - 3 hours a week for 4 – 6 weeks;
    - On-going support - 4 hours per month.

**Patient and Family Advisory Council Liaison**
- Works closely with the sponsor to develop the plan and timeline to initiate the PFAC and get the ‘right’ people on the steering committee and planning committee.
- Attends *Facilitation Skills for Leaders* offered by BJC Learning Institute.
- Coordinates the distribution of research.
- Provides a readiness assessment to staff.
- Creates a business case/charter for the formation of the planning committee and PFAC.
- Leads the planning committee meetings; establishes expected outcomes for each meeting.
- Facilitates the steering committee meetings.
- Coordinates the recruitment, interview, selection and orientation process for PFAC members.
- Assist the co-chairs of the PFAC in planning and facilitation of the monthly meetings.

  - **Time commitment:**
    - Preparation Phase – 7-8 hours per week for 4 weeks;
    - Planning phase – 8 – 10 hours per week for 8 weeks;
    - On-going support – 2-3 hours per week.

**Steering Committee Members (composed of leaders and change managers of the organization)**
- Provide guidance and review recommendations from the planning committee and the PFAC.
- Attend scheduled steering committee meetings.

  - **Time commitment:**
    - Preparation/Planning Phase- 3 monthly meetings for 90 minutes.
    - On-going support – quarterly meetings for 90 minutes
• Planning Committee Members (composed of 4-5 front-line staff and 4-5 patients/family members)
  o Assist with the development of the structure for the PFAC (membership, frequency of meetings, length of meetings).
  o Create a brochure for the PFAC to be used during the recruitment process and for acceptance planning.
  o Construct a mission statement, vision statement, goals and bylaws for the PFAC.

  ▪ Time commitment:
    • Planning Phase only - 6-8 weekly meetings for 2 hours each including some homework between meetings.

• Patient and Family Advisory Council Members
  o Opportunities could include but are not limited to:
    ▪ Develop patient and family education and communication materials.
    ▪ Generate new program ideas to benefit patients, family members and caregivers.
    ▪ Enhance ongoing collaboration and cooperation among clinicians, patients and families.
    ▪ Participate in the development and planning of patient and family satisfaction initiatives, new facilities and facility renovation.
    ▪ Promote awareness of opportunities and key resources that will help patients and family members navigate through the system.

  ▪ Time commitment:
    • Monthly meeting for 2 hours. Could include additional responsibilities such as participation in hospital committee meetings, PFAC task group meetings, or research.

• Patient and Family Advisory Council Assistant
  o Coordinates the meeting rooms.
  o Orders food for meetings.
  o Sends correspondence (i.e. agenda, meeting minutes, etc.)

  ▪ Time commitment:
    • Planning Phase – 5 hours per week
    • Initiate Phase – 1-2 hour per week

• Neutral Facilitator
  o Helpful for the pre-planning/planning phase of the PFAC process.
  o Assists with guiding group and meeting desired outcomes for each meeting.
  o Consider recruiting Skunks Team member, or other resource with proven facilitation skills.
Sample Budget for Patient and Family Advisory Council

Staff Time:

PFAC coordinator  Planning and Initiate Phase – 8-10 hours/week
($ ____ x 10 hours x 12 weeks = ____ )
2-3 hours a week for on-going PFAC

Assistant   1-2 hours a week

Non-exempt staff   2-3 hours per week for Planning and Initiate Phase
3 hours per month for on-going PFAC

Expenses:

Meals for 22 people attending 9 meetings 2,600.00
@ 12.95 per person (planning committee)

Meals for 22 people attending 12 meetings 3,500.00
@ 12.95 per person (PFAC meetings)

Office supplies (PFAC manuals), copies for, 2,500.00
presentations/agendas, flip charts, educational
materials about advisory councils, printing for
PFAC brochures

Gifts for patient/family members 500.00

Conferences (one each year) 5,000.00
1 council member with PFAC coordinator
@ 2,500 each
Institute for Family Center Care or
Institute for Healthcare Improvement

Partnering with patients and families to improve care Priceless!!!

Total $14,000.00
Sample PFAC Organizational Structure

Senior Leadership

PFAC Steering Committee
President or VP, Service Line Director(s), Volunteer Services Rep, Patient Advocate, Department Manager, Physician, PFAC Liaison

PFAC Planning Committee
Patient/Family Representatives (4-6 members)
Front Line Staff (4-6 members)
Department Manager/Director
PFAC Liaison

Patient and Family Advisory Council (PFAC)
Front Line Staff
Patient and Family Members
Senior Leadership (VP or President)
Service Area Director
Physician Representation
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**Key:**
- **Projected Plan**
- **Task Ongoing**
- **Task Complete**
STEP 1. Obtain Hospital Leadership Support/Select a Sponsor
The first steps to creating a Patient and Family Advisory Council can be the hardest and the most important. A critical factor to the success of the council is to have leadership support the principles of partnering with patients and families. Leadership must be engaged in the promotion of the PFAC and must set the vision for the team. Leadership can have different titles/roles depending on the organizational structure. At minimum you need support from:

- Department supervisor and or managers.
- Hospital director and/or VP.
- Hospital president.
- Physician leadership(formal and informal physician leaders).

STEP 2. Form a Steering Committee
During the development of the PFAC, it is necessary to get input and buy-in from key stakeholders. The process of change indicates that key stakeholders need to be involved in the formation of the PFAC concept and plan. This tool kit suggests that a steering committee of stakeholders be formed to help develop the concept of partnering with patients and families and then spread these thoughts to other staff. These stakeholders should include but not be limited to leadership over direct care areas, physicians, and front-line staff who are influencers over peers. Some qualities these stakeholders should possess are openness to change and expression of value in engaging patients and families in treatment decisions.

The role of the steering committee will be to guide you during the PFAC planning process and during the initiation of the PFAC. The role of the steering committee is not to give approval, but to brainstorm ways to overcome barriers and capitalize on positive aspects of the PFAC.

A stakeholder is any person or group that is:

- Likely to be affected, positively or negatively, by the activities of the PFAC.
- In a position to assist or block achievement of the outcomes.
- An expert or has special resources that could greatly affect the quality of the end product/service.
- A “thought-leader” with significant organizational influence.

STEP 3. Select a Coordinator/Liaison
It is imperative to select a coordinator who can promote the value of patient and family-centered care. Characteristics of an ideal coordinator are:

- Passion for patient and family-centered care.
- Available time for PFAC activities.
- Decision-maker who is respected among peers.
- Possesses excellent communication and facilitation skills.
- Knowledge of the operational and clinical areas of services provided.
- Motivator.
STEP 4. Conduct Research
Prior to starting a PFAC, it is helpful to gather information from other healthcare organizations about lessons learned and benefits of this partnership. Site visits or conference calls can provide insight into potential opportunities and pitfalls. Within the BJC system, there are many opportunities to learn from peers who have initiated advisory councils. Throughout the county, more and more hospitals have seen the benefit of working with patients and families through advisory councils; they are open to sharing their experiences. The attached appendix has a listing of contact names within and outside of BJC. In addition, there are informational websites and articles for review. It is highly recommended that everyone view the 13-minute video on patient and family-centered care produced by The American Hospital Association.

STEP 5. Perform Readiness Assessment
This readiness assessment is helpful in understanding the magnitude of change required to prepare staff for this partnership with patient and families. A variety of tools and techniques can be used to assess for readiness. The team could meet to do a threat/opportunity matrix, situation appraisal, or potential opportunity analysis. Another approach would be to conduct staff surveys, a stakeholder analysis, or talk about creating the PFAC at a staff meeting to gauge the level of support. It is important to understand and review possible barriers to introducing a PFAC and brainstorm ways to minimize these barriers. The tab following this section includes information about the tools listed above. Each service area will need to determine the tool set that will best fit their needs.

STEP 6. Create a Business Case or Charter
Organizations should be clear about why they are starting a PFAC. One way to summarize the reasons is to complete a business case or charter. A business case is a justification for adopting a change. Usually business cases document how the change will reduce costs, increase revenue, and address business or strategic advantages. This “template” can be difficult to complete when talking about creating a partnership with our patients and families. Some questions to think about when forming your business case are:
1. How could the PFAC further your organization\department’s goals?
2. What are the potential benefits?
3. What are the potential costs?
4. What are the direct and indirect effects that a PFAC will have on the organization?
5. What are the risks?
6. How will we measure the impact of the PFAC?

A charter can be also be used instead of a business case to justify the need for an advisory council. Use of a charter can help to define and clarify the organization’s vision for partnering with patients/families through an advisory council model. The charter is a one page document that includes the following components:
- An opportunity/problem statement.
- Scope.
- Goals.
- Estimated benefits.
- Timeline with a start date for the first PFAC meeting.
- Listing of planning committee team members.
• Engage stakeholders early in the process.
• Clearly define the role of the PFAC.
• Find a physician champion to articulate the need for the advisory council.
• Select a coordinator with an understanding of the role of the council and a strong passion for patient and family-centered care.
• Be prepared to explain how the council will provide improvements and how success will be measured.
# Pre-Planning Checklist

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<th>Activity</th>
<th>Owner</th>
<th>Target Date</th>
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<tr>
<td>Determine leader who will ensure the initiation and continued success of the PFAC.</td>
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<tr>
<td>Form a steering committee composed of leadership, physicians and front-line staff.</td>
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<td>Select a coordinator/liaison for the PFAC.</td>
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<td>Identify key stakeholders.</td>
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<td>Conduct research on patient and family advisory councils and patient and family-centered care.</td>
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<td>Gather and distribute informational articles about PFAC.</td>
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<tr>
<td>Create a Business Case/Charter for PFAC.</td>
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<tr>
<td>Contact peers who have been involved in creating a PFAC (see contact list in Resources).</td>
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<tr>
<td>Select patients, families and staff to be part of the planning committee (utilize current hospital volunteers, ask for names of potential candidates from staff).</td>
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<tr>
<td>Recruit patients, families and staff for the planning committee, inform them of dates/times of meeting.</td>
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<td>Perform readiness assessment with hospital staff.</td>
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<td>Recruit members for steering committee and meet at least 1 time with steering committee during pre-planning phase.</td>
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<td>Obtain commitment of funds for supplies, copying, manuals and refreshments for meetings.</td>
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<tr>
<td>Obtain a commitment for meeting space for weekly planning committee meetings.</td>
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<tr>
<td>Start recruitment of patients and families to the PFAC.</td>
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<td>Prepare for acceptance planning.</td>
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Patient and Family Advisory Council
Barnes-Jewish St. Peters Hospital

What is a Patient and Family Advisory Council?
Direct Link to Relationship Based Care

- Patient and family an equal part of the care giving team.
- No current way to obtain on-going feedback from our partners.
- The Patient and Family Advisory Council will fill this gap.
Guiding Principles
Patient and Family Centered-Care

Collaboration  Dignity and Respect
Participation  Sharing Information
The provision of care is not the same as the experience of the illness—both perspectives are needed.

Patients and families are part of their care and we as caregivers are part of their experience.

Taken from Calgary Health Region Presentation – IHI 2007
Patient and Family-Centered Care

The Institute of Medicine’s 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, called for health care systems that:

- Respect patients’ values, preferences and expressed needs to be involved in their care
- Provide the information, communication, and education that people need and want
- Guarantee physical comfort, emotional support, and the involvement of family and friends
- Provide transformational change in healthcare
What is a Patient and Family Advisory Council?

- Comprised of patients, families, clinicians, staff and administrators
- Serves as a voice for patients and family members
- Works together to deliver the highest quality care possible for our patients
- Provides shared expertise!
Council Structure

- Composition should reflect their constituencies
  - Size: 8 – 25 members

- Staff participation
  - 2 to 3 or more patients/family members to 1 staff
  - Include executive leadership
  - Other staff encouraged periodically to attend as guests

- Established terms of membership

- Staff liaison

- Chair or co-chairs
  - Establish agenda in conjunction with staff liaison
Embracing Change

- Involves a cultural shift
- Hearing about expectations of patients and families
- Listening to stories of patients and families
- Altering expectations of healthcare professionals
- Becoming comfortable with uncertainty
- Honoring each other’s expertise
- Understanding . . . Then bridging the gap
Patient and Family Advisory Councils Make Sense!

- Patient satisfaction surveys can provide retrospective feedback
- Need is for real time, ongoing patient and family feedback into organizational initiatives
- More than just a snapshot!
- BJC community hospitals are pioneers in the St. Louis metro area
The Voice of the Patient and Family Member Can Make a Difference

- Increase patient satisfactions scores
- Improve safety and quality
- Prevent malpractice and litigation
- Reduce costs by streamlining care
- Improve the experience for patients and family members
- Increase work satisfaction for staff and physicians
Patient and Family Advisory Councils Exist Today

- Providence Regional Medical Center
  - Inpatient Advisory Council
    - Everett, Washington

- Dana Farber Cancer Institute
  - Cancer Care Advisory Council
    - Boston, Massachusetts

- Massachusetts General Cancer Center
  - Cancer Care Advisory Council
  - Cardiac Advisory Council
    - Boston, Massachusetts

- Many more . . . just google
BJC Advisory Councils:

- St. Louis Children’s Hospital
  - Inpatient Family Advisory Councils
  - Involvement in unit based teams

- Missouri Baptist Medical Center
  - Cancer and Infusion Center
  - Inpatient Patient and Family Advisory Council

- Christian Hospital
  - Cancer Care Center

- Barnes Jewish St. Peters Hospital
  - Siteman Cancer Center
  - Inpatient Patient and Family Advisory Council

- Parkland Health Center
  - Preparation for Inpatient Patient and Family Advisory Council
  - Preparation for Oncology Patient and Family Advisory Council
BJSPH Steps to PFAC

1. Present PFAC project to leadership.
2. Find owner for PFAC
3. Form Steering Committee
4. Form Planning Committee
5. Hold Planning Committee meetings x8
6. Present final proposal to leadership

Create Patient and Family Advisory Council
Proposed Timeline

- Select PFAC Coordinator
- Create Steering Committee
- Create Planning Committee
- Planning Committee Meetings x8
- Present Final Proposal
Budgeted Expenses

- Staff Resources
  - PFAC Coordinator - 0.5 FTE during planning phase
  - Clerical Support -
  - Front-line staff – 2-3 hours per month

- Marketing support
  - Brochures/printing

- Orientation
  - TB testing/Flu shot

- Meals

- Office supplies
  - Manuals, education materials, flip charts, copies

- Gifts for Planning Committee Members

- Attachment – sample budget
What Do We Need From the Steering Committee:

- Approval to move forward
- Become a champion for the PFAC
- Commitment to transparency and openness
- Assistance to break down barriers
- Resource allocation (coordinator, leadership, front-line staff, clerical support, financial)
- Referrals of patients/families to PFAC
Goals of the Planning Committee

- Learn about PFAC and Relationship Based Care concepts
- Define the goals, mission, responsibilities and expectations of the Patient and Family Advisory Council
- Identify the structure of the council
  - Number of members
  - Length of terms
  - Application process
  - Length and frequency of meetings
Members of Planning Committee

- **Patient and Families**
  - Barb and John Giblin
  - Charlene Aslinger
  - JD Price
  - Dororthy Brown
  - Mary Huesing

- **Staff**
  - Angie Hendricks
  - Marie Stiffler/Deanna Vollmar
  - North staff person/Karen Sy

- **Administration**
  - David Ross?
Critical Success Factors/Lessons Learned

- Critical Success Factors
  - Choosing the right patients, staff and family members
  - Ongoing leadership commitment
  - PFAC is perceived as credible and viable
  - Staff engagement

- Lessons Learned
  - Need the engagement of leadership and physicians
  - Clearly define the role of the PFAC
  - Select a coordinator with an understanding of patient and family-centered care
  - Be prepared to explain how success is measured
Potential Challenges

- Lack of commitment from staff, patients, families, leadership.
- Fear that patient’s and families’ suggestions will be unreasonable.
- Lack of a guiding vision.
- Scarce fiscal resources and competing priorities.
- Tendency to implement a top-down approach to initiating partnerships with patients and families.
Next Steps

- Obtain feedback from Steering Committee
- Obtain approval to move forward
- Start planning committee meetings
- Provide resources to planning committee
STEP 1. Form a PFAC Planning Committee
Once leadership approval is obtained, the planning begins. A planning committee is formed with a goal of creating the foundation/structure of your actual PFAC. This planning committee is comprised of staff, patients and families. **Chose members of the PFAC Planning Committee wisely! This is a critical success factor for overall success of your PFAC.** Steps to planning committee creation follow:

A. Create a communication plan for your planning committee. This includes a packet of information used for recruitment purposes. Includes goals of the planning committee, definition and role of a PFAC, responsibilities of a planning committee member, etc.

B. Create planning committee binders

C. Recruit planning committee members
   a. Referrals from staff or physicians
   b. Suggested members include:
      i. PFAC c; front line staff, physician, manager
      ii. Five to six patients or family members (representing different diagnoses, a diverse cross section of your patient population).
         **This is a critical piece. Do not rush through your patient/family selection!**
      iii. Characteristics of planning committee members: positive approach, ability to share information in a group, good listening skills; non-judgmental, ability to work with people whose backgrounds are different from their own

D. Begin planning committee meetings (8 weeks)

STEP 2. Start Recruitment of Patients and Families to the Advisory Council
The membership of the council is critical to the success of building a partnership between the providers and the patients/families. You will want to take time to recruit members for the council, seeking patients and families who represent a variety of clinical experiences such as type of illness, and program utilized. Include patients and families who have both positive as well as negative perceptions of experiences. Strive for patients and family members to be the majority of the committee’s membership.

Seek patients and families who reflect the diversity of those served by the hospital service line (consider racial, cultural, religious, socioeconomic, age, educational background, etc).

All potential candidates will need to complete an application and be interviewed by select members of the planning committee (see attached sections for examples of applications and interview questions).

Seek individuals with the following qualities:

- Ability to share insights and information about their experiences in ways that others can learn.
- Sees beyond their own personal experiences.
- Shows concern for more than one issue or agenda.
- Demonstrates good listening skills.
- Respects the perspective of others.
• Speaks honestly, comfortably in a group.
• Interacts well with many different types of people.
• Works in partnership with others.
• Ability to share their story in a meaningful way.

Suggestions for recruitment:
• Ask staff and physicians for suggestions.
• Consider patients and families from the planning committee.
• Contact patient or family networks, support groups, or advocacy organizations.
• Place a story in the community newspaper and hospital publications.
• Post information about the advisory council on the hospital’s website.
• Ask other patients and families who are already involved if they have a friend who might be interested in participating.
• Ask community and church leaders.
• Distribute PFAC brochures to key areas (waiting rooms, physician offices, patient care unit).

STEP 3. PFAC Orientation
When members join a council, they should receive a thorough orientation, not only to the purpose and work of the council, but also to the “culture” of the organization and the responsibilities of their new role. The advisory council members will be part of the volunteer services of the hospital and will need to be oriented in their role as a hospital volunteer (not necessary for staff members). They will also need to get a background check, flu shot and TB testing. Coordination between the PFAC liaison and volunteer service needs to occur so that the PFAC member meets the orientation requirements as a hospital volunteer.

Orientation should include:
• Introductions and the sharing of personal and family stories.
• The vision and goals of the organization and the council.
• Their role as a volunteer.
• Review of hospital service/safety standards.
• The role of the council, how it fits within the organization’s structure.
• The roles and responsibilities of members.
• HIPAA and expectations for honoring privacy and confidentiality.
• Review of bylaws.
• The roles and responsibilities of staff on the council.
• How to be an effective council member.
• How to present issues effectively.
• How to be effective in collaborating together.
PLANNING PHASE: LESSONS LEARNED

- Continue to keep council visible. Discuss role of council in department meetings and leadership meetings in order to build a strong foundation.

- Involve clinicians in laying the groundwork for the PFAC by having them nominate potential members.

- Continue to work on the communication plan regarding the start-up of the PFAC.

- Start early with recruitment of PFAC patient and family members to give yourself enough time to find the people with the passion and experience.

- Work closely with volunteer services to organize orientation for the PFAC members.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Owner</th>
<th>Target Date</th>
<th>Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organize planning committee binders - Include agenda, contact info,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>articles, websites, presentations, timeline, dates/time of meetings.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Send welcome letter to planning committee members.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Convine planning committee meetings - Conceptualize structure of PFAC.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create a communication plan to gain buy-in for the PFAC concept.</td>
<td></td>
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</tr>
<tr>
<td>Contact Volunteer Services to help coordinate orientation of PFAC members.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Planning Committee Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review stakeholder analysis.</td>
</tr>
<tr>
<td>Create PFAC brochure.</td>
</tr>
<tr>
<td>Develop mission, vision and goals for PFAC.</td>
</tr>
<tr>
<td>Review and adjust bylaws.</td>
</tr>
<tr>
<td>Brainstorm ideas for metrics.</td>
</tr>
<tr>
<td>Review information gathered from readiness assessment.</td>
</tr>
<tr>
<td>Provide guidance on recruitment and interview process.</td>
</tr>
<tr>
<td>Assist in creating education plan for staff regarding role of PFAC.</td>
</tr>
<tr>
<td>Create PFAC patient/family letter and application.</td>
</tr>
<tr>
<td>Continue with Recruitment of patients and families to the PFAC.</td>
</tr>
<tr>
<td>Prepare for celebration at last meeting. May want to take pictures throughout the process.</td>
</tr>
<tr>
<td>Purchase gift for participants.</td>
</tr>
</tbody>
</table>
Planning Committee Meetings – weekly 2 hour meeting

**Suggested Agendas**

<table>
<thead>
<tr>
<th>Week 1</th>
<th>Week 2</th>
<th>Week 3</th>
<th>Week 4</th>
<th>Week 5</th>
<th>Week 6</th>
<th>Week 7</th>
<th>Week 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome and introductions</td>
<td>Guest speaker from existing PFAC</td>
<td>Patient Journey Exercise (defines potential scope)</td>
<td>Vision and Mission Statement Creation</td>
<td>Define Goals and Resp</td>
<td>Review Steering Committee meeting</td>
<td>Define recruitment and interview process</td>
<td>Review outstanding to do’s</td>
</tr>
<tr>
<td>Review PFAC concepts</td>
<td>Develop operating agreement</td>
<td>Review Stakeholder Analysis/add new stakeholders</td>
<td>Brainstorm ideas for goals and metrics</td>
<td>Review Readiness Assessment</td>
<td>Review bylaws/structure</td>
<td>Ideas for educational plan for staff</td>
<td>Present final PFAC proposal</td>
</tr>
<tr>
<td>Goals of planning committee</td>
<td>Review org/department structure</td>
<td>SEE Hear Feel Exercise for vision</td>
<td>Begin creating PFAC brochure</td>
<td>Prep for Steering Committee Presentation</td>
<td>Complete PFAC brochure</td>
<td>Invite leadership for celebration</td>
<td></td>
</tr>
<tr>
<td>View family-centered video</td>
<td>Define patient population</td>
<td>Define Vision Statements</td>
<td>Review homework*</td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

* Homework:
  - Planning committee members email sample vision statements to liaison
  - Patients and families start working on short bio an answer question, “what is the value of a PFAC?”

**PFAC STEERING COMMITTEE COMMUNICATION**

Recommend touching base with your steering committee three times during the planning stages of PFAC journey:
1. Prior to beginning the planning meetings.
2. Midway through the planning committee phase (can do this via email).
3. After planning committee finalizes the PFAC proposal.

The role of the steering committee should be re-evaluated after the PFAC proposal is finalized.
Patient and Family Advisory Council Planning Committee

Date: June 25, 2009
Time: 5:30 – 7:30 PM
Location: Healthwise POB 1, First Floor

Purpose: To begin developing relationships with each other and understand the function of the Patient and Family Advisory Council (PFAC) Planning Committee.

Desired Outcomes: By the end of this meeting, we will:
- Meet and learn about each other.
- Gain knowledge of Patient and Family Advisory Councils.
- Understand your role on the PFAC Planning Committee.

<table>
<thead>
<tr>
<th>Topic / Content</th>
<th>Deliverables / Desired Outcome</th>
<th>Materials / Tools, Process</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome and Introductions</td>
<td>Meet each other</td>
<td>Karen - verbal</td>
<td>5:30 – 5:45 pm 15 mins</td>
</tr>
<tr>
<td>Mission Moment</td>
<td></td>
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</tr>
<tr>
<td>Overview of Patient and Family Advisory Councils</td>
<td>Gain information about Advisory Councils/roles of Planning Committee members</td>
<td>Laurie – Handout and presentation</td>
<td>5:45 – 6:00 pm 15 mins</td>
</tr>
<tr>
<td>Remaking of American Medicine</td>
<td>Gain information about Advisory Councils</td>
<td>Karen/Laurie – Video</td>
<td>6:00 – 7:15 pm 75 mins</td>
</tr>
<tr>
<td>Hand in Hand</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timeline and Meeting Schedule</td>
<td>Review timeline Dates and times of future meetings</td>
<td>Karen - Planning Committee Manual</td>
<td>7:15 – 7:25 pm 10 mins</td>
</tr>
<tr>
<td>Questions and Comments</td>
<td>Answer outstanding concerns</td>
<td>Karen/Laurie</td>
<td>7:25 – 7:30 5 mins</td>
</tr>
</tbody>
</table>

Next Steps:
- Read articles in manual
- Research information on Patient and Family Advisory Councils
- Next Planning Committee Meeting July 2

This GROUPER/GOACT template is found on Transformation Station at http://bjcnetnew.carenet.org/sites/LeanSigmaTransformationStation/default.aspx
Planning Committee-Patient and Family Advisory Council
Barnes Jewish St. Peters Hospital

Welcome!
The provision of care is not the same as the experience of the illness—both perspectives are needed.

Patients and families are part of their care and we as caregivers are part of their experience.

Taken from Calgary Health Region Presentation- IHI 2007
What is a Patient and Family Advisory Council?

- Comprised of patients, families, clinicians, staff and administrators
- Serves as a voice for patients and family members
- Work alongside nurses, doctors and other staff to deliver the highest quality care possible for our patients
- Shared expertise!
What is a Patient and Family Advisory Council?

Purpose –

To serve as a formal mechanism for involving patients, family and staff as partners for policy and program decision making in healthcare settings.
Different Types of Councils

- Composition:
  - Patient and family
  - Parent and family
  - Adolescent and/or children

- Group varies in size, form, structure and name
Council Structure

- Composition should reflect their constituencies
  - Size: 8 – 20 members

- Staff participation
  - 2 to 3 or more patients/family members to 1 staff
  - Include executive leadership
  - Other staff encouraged periodically to attend as guests

- Terms of membership
- Staff liaison – that’s Karen!
- Chair or co-chairs
  - Establish agenda in conjunction with staff liaison
Dana-Farber and Massachusetts General
PFAC 2007 Initiatives

- Dana-Farber
  - Patient guide redesign
  - Participation in major design and construction project
  - Side by Side newsletter

- Massachusetts General
  - Developed program for cancer survivors
  - Assisted with the production of educational videos
  - Participate in the monthly orientation of all new staff
Patient and Family Advisory Councils Exist Today!

- Dana Farber Cancer Institute
- Massachusetts General Cancer Center
- H. Lee Moffitt Cancer Center and Research Institute
- Calgary Health Region
- University Rochester Medical Center
- Cincinnati Children’s Hospital
BJC Advisory Councils:

- **St. Louis Children’s Hospital**
  - Inpatient Family Advisory Councils
  - Involvement in unit based teams

- **Missouri Baptist Medical Center**
  - Cancer and Infusion Center
  - Inpatient Patient and Family Advisory Council

- **Christian Hospital**
  - Cancer Care Center

- **Barnes Jewish St. Peters Hospital**
  - Siteman Cancer Center
  - Inpatient Patient and Family Advisory Council

- **Parkland Health Center**
  - Preparation for Inpatient Patient and Family Advisory Council
  - Preparation for Oncology Patient and Family Advisory Council
Patient and Family Advisory Council – Why?

- Institute of Medicine 2001 report - Crossing the Quality Chasm
  - Transformational change in healthcare
  - Need to establish new partnerships with patients and families
  - Recommended that patients and families be more involved in decisions about their health care
- Move towards patient and family centered care model
## Patient and Family Centered Care-Principles

<table>
<thead>
<tr>
<th>Communication</th>
<th>Respectful Relationships</th>
<th>Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listen to patients\families</td>
<td>Based on compassion, dignity and trust</td>
<td>Staff, patients and families form an alliance</td>
</tr>
<tr>
<td>Sharing information</td>
<td>Honor patient and family perspectives and choices</td>
<td>Mutually beneficial partnerships are created between staff and patients and families</td>
</tr>
<tr>
<td>Meaningful dialogue between patient, families and healthcare providers</td>
<td></td>
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</tr>
</tbody>
</table>
“The voice of the patient is dominant here. One patient doesn’t speak for all patients so it is important to bring together as many people as you can. The patients and families are who we check with on everything we do.”

Quote from Jim Stam
Dana-Farber PFAC Co-chair
Patient and Family Advisory Council Makes Sense!

- Patient satisfaction surveys can provide retrospective feedback
- Need is for real time, ongoing patient and family feedback into organizational initiatives
- More than just a snapshot!
- Patient and Family Advisory Council will allow us to achieve this......
Goals of the Planning Committee

- Define the goals, mission, responsibilities and expectations of the Patient and Family Advisory Council

- Define the structure of the council
  - Number of members
  - Length of terms; application process
Planning Committee

- Proposed Patient and Family Advisory Council structure will be presented to:
  - Executive Team
  - Steering Committee
- Discuss feedback
- Council structure approved
- Goal for first Council meeting in October 2009
Thank you for your participation as we partner together to improve healthcare!
Let’s Dance!!

Embracing patient partnership
<table>
<thead>
<tr>
<th>ED</th>
<th>Direct Admit</th>
<th>Admission (transfer to unit)</th>
<th>Treatment/Care</th>
<th>Discharge</th>
<th>Follow up</th>
</tr>
</thead>
</table>
| **Personnel** | 1. Triage Nurse  
2. Emergency Nurse  
3. Emergency Doctor  
4. EKG Technician  
5. Lab Technician  
6. X-Ray Technician  
7. Registration  
8. Security  
9. Respiratory  
10. Cardiac Cath Lab | **Personnel** | 1. Registration  
2. Nurse  
3. Lab | **Pluses** | 1. Communicate with doctor  
2. Told about admission  
3. Relief of being admitted  
4. Family likes to know what is going on  
5. Family like questions answered | **EBI** | No handoffs in front of me |
| **Pluses** | 1. Quick Response  
2. Staff thorough  
3. Took patient first and then did registration  
4. Family felt welcomed  
5. Staff listened to family  
6. Family/Patient felt reassured of care  
7. Staff gave updates  
8. Staff attentive  
9. New registration process only takes 3 minutes to register patient | **EBI** | Treatment was late and slow | **EBI** | No additions from previous list |
| **EBI** | 1. Phone calls at 1:00 am-Scary  
2. Long wait in Emergency  
3. No beds on floor  
4. Need to ask if | **Pluses** | 1. Communicate with doctor  
2. Told about admission  
3. Relief of being admitted  
4. Family likes to know what is going on  
5. Family like questions answered | **EBI** | No handoffs in front of me |
| **Personnel** | 1. Lab  
2. Housekeeping  
3. Coumadin Clinic  
4. Food Services  
5. Nurse  
6. Nurse techs  
7. Doctors  
8. Radiology  
9. Respiratory  
10. CardioPulm  
11. EKG techs  
12. Pastoral care  
13. Volunteers  
14. Cookie lady  
15. Hospital operators  
16. Endoscopy  
17. Pathology  
18. Social Services  
19. Physical Therapy  
20. Patient care tech | **EBI** | 1. Communicate with doctor  
2. Told about admission  
3. Relief of being admitted  
4. Family likes to know what is going on  
5. Family like questions answered | **EBI** | No handoffs in front of me |
| **Pluses** | 1. Staff was pleasant  
2. Told about admission  
3. Relief of being admitted  
4. Family likes to know what is going on  
5. Family like questions answered | **EBI** | No handoffs in front of me |
| **Personnel** | 1. Doctor  
2. Nurse  
3. Case coordinator  
4. Social Service  
5. Home Health Care  
6. Patient care tech | **Pluses** | 1. Patient education sheets on discharge papers  
2. Helped with discomfort to take MRI  
3. Med list had wrong meds listed on it  
4. Waiting on a wheelchair  
5. MRIs scary  
6. Multiple doctors needed to discharge a patient  
7. Staff relay to patient how long it will take to discharge  
8. Wheel chair ready but not able to get discharged  
9. Don’t discharge people after midnight |
| **EBI** | 1. Extraordinary Care from Cardiologist  
2. Doctors answered questions and took time to listen  
3. Treats patient with respect  
4. Follow Up doctor appointment made in the hospital  
5. (To follow up Call)- Timing of call was perfect  
6. (To follow Up Call) – Surveyor made sure patient received same home health worker  
7. Thank you Cards | **EBI** | No handoffs in front of me |
| **Personnel** | 1. Caregivers  
2. Home Health  
3. Follow up from Floor  
4. Patient Advocate  
5. Physical Therapy  
6. Nurse  
7. Physician  
8. Surveyor Call |

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07/09/2009
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<tbody>
<tr>
<td>5.</td>
<td>Staff taking too long to register patient</td>
<td>1.</td>
<td>Have more than one surgeon who can do surgery</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Staff (Volunteer) not knowing how to use the computer</td>
<td>2.</td>
<td>Have doctors take bedside manner classes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>open EBI</td>
<td>3.</td>
<td>Staff were aware of Dr behavior and did nothing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.</td>
<td>Let patient know who they can call when problems arise</td>
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<td></td>
<td></td>
<td>5.</td>
<td>Food service in a rush</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>6.</td>
<td>Don’t always get what you ordered for a meal</td>
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<tr>
<td></td>
<td></td>
<td>7.</td>
<td>Staff flipping lights on during the night</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>8.</td>
<td>No newspaper</td>
<td></td>
</tr>
</tbody>
</table>
Table 1. Cancer Patient/Family Member Journey Exercise – Lists entities/people came in contact with during journey and begins to include Even Better Ifs (EBIs)

<table>
<thead>
<tr>
<th>Pre Diagnosis</th>
<th>Diagnosis</th>
<th>Treatment Planning</th>
<th>Treatment</th>
<th>Remission/Follow Up</th>
<th>Palliative/Supportive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammmogram</td>
<td>Doctors</td>
<td>Getting a porta-cath</td>
<td>Rad Oncology</td>
<td>Doctors</td>
<td>Hospice</td>
</tr>
<tr>
<td>Echo cardiogram</td>
<td>Oncology Nurse</td>
<td>Cocktail mix</td>
<td>Doctor’s Offices</td>
<td>Labs</td>
<td>Spiritual</td>
</tr>
<tr>
<td>Diagnostic Mamm</td>
<td>Receptionist at office</td>
<td>Radiation marking</td>
<td>OP Infusion</td>
<td>Diagnostic testing</td>
<td>Home care</td>
</tr>
<tr>
<td>Ultrasound (internal)</td>
<td>Triage Nurse (Dr. office)</td>
<td>Blood (drawn for self)</td>
<td>4th Floor Inpatient Surgery (portacath or tumor removal)</td>
<td>Rad Oncology</td>
<td>Message therapy</td>
</tr>
<tr>
<td>Primary Care Physician</td>
<td>Lab results</td>
<td>Nutrition (diet consult)</td>
<td>Medical Oncology</td>
<td>Maintenance meds</td>
<td>Durable med equipment</td>
</tr>
<tr>
<td>Surgeon</td>
<td>Pharmacy</td>
<td>Clinical Trial</td>
<td>Resources to help with</td>
<td>Pharmacy</td>
<td>Doctors</td>
</tr>
<tr>
<td>Breast MRI (MRI)</td>
<td>Surgery</td>
<td>Labs</td>
<td>bills</td>
<td>Doctors</td>
<td>Advance Directive</td>
</tr>
<tr>
<td>Oncologist</td>
<td>Inpatient Stay</td>
<td>Treatment Planning CT – for Radiation</td>
<td>Lab</td>
<td>Radiation marking</td>
<td>Power of Attorney</td>
</tr>
<tr>
<td>Biopsy</td>
<td>PET Scan</td>
<td>Xrays</td>
<td>Shot to build blood counts</td>
<td>Pharmacy</td>
<td>Review of financial affairs</td>
</tr>
<tr>
<td>Spinal Tap</td>
<td>Out patient Services</td>
<td>Coordination of Care</td>
<td>Coordination of Care</td>
<td>Community Organizations</td>
<td>Last rights</td>
</tr>
<tr>
<td>Urologist</td>
<td>PET Scan</td>
<td>Care</td>
<td>Radiation Pharmacy</td>
<td>Dry skin</td>
<td>Social services</td>
</tr>
<tr>
<td>Bone Scan</td>
<td>CT Scan</td>
<td>Social Worker</td>
<td>Diagnostic testing</td>
<td>Radiation marking</td>
<td>Friends and family</td>
</tr>
<tr>
<td>Lab Work - Pathology</td>
<td>PET Scan</td>
<td>Physicians</td>
<td>Dealing with bills</td>
<td>Blood</td>
<td>Education – end of life care</td>
</tr>
<tr>
<td>Chest X-ray</td>
<td>PET Scan</td>
<td>Social Worker</td>
<td>Checking out other sources of funding</td>
<td>Social Worker</td>
<td>Financial – Wills</td>
</tr>
<tr>
<td>CT Scan</td>
<td>PET Scan</td>
<td>Social Worker</td>
<td>Durable medical equipment</td>
<td>Rad Oncologist</td>
<td>Supportive care for family</td>
</tr>
<tr>
<td>Screening – annual PSA</td>
<td>PET Scan</td>
<td>Social Worker</td>
<td>Cancer resource ctr</td>
<td>Surgeon/Hematologist/</td>
<td>Pluses Streamlined so family didn’t have to arrange</td>
</tr>
<tr>
<td>Community Screening</td>
<td>MD’s &amp; RN’s – you felt</td>
<td>Social Worker</td>
<td>Social Worker</td>
<td>Rad Oncologist worked</td>
<td>EBI Facilitate advance directive</td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>Home to check status</td>
<td>Social Worker</td>
<td>Social Worker</td>
<td>together to determine treatment</td>
<td>ACTION – help pts create one if they don’t have one</td>
</tr>
<tr>
<td>Pathology</td>
<td>Felt protected by doctor</td>
<td>Tumor Board</td>
<td>Home treatments</td>
<td>Rad Oncology</td>
<td>Pre-arranged funeral plans and discussions</td>
</tr>
<tr>
<td>MRI</td>
<td>because of communication between physicians</td>
<td>Clinical Desktop</td>
<td>Home health</td>
<td>Diagnosis</td>
<td>ACTION – delicate matter, we should talk to counselors to determine how to approach this</td>
</tr>
<tr>
<td>Spiritual help (thru all processes)</td>
<td>Liked white board for information on staff</td>
<td>MD’s &amp; RN’s – you felt like you knew them when you arrived</td>
<td>Insurance</td>
<td>E.R.</td>
<td>Warning about scams after pt dies</td>
</tr>
<tr>
<td>Internal ultrasound</td>
<td>Financial Person</td>
<td>Communication between office – coordination of care</td>
<td>E.R.</td>
<td>Late effects of treatment</td>
<td>ACTION – research and create document for pt</td>
</tr>
<tr>
<td>Search intranet</td>
<td>Education</td>
<td>Pluses</td>
<td>Grief counseling for family</td>
<td>Pluses</td>
<td>Protection of assets</td>
</tr>
<tr>
<td>Pluses</td>
<td>Nurses in back of office</td>
<td>Surgeon/Hematologist/</td>
<td>E.R.</td>
<td>Celebrate getting thru treatment</td>
<td>EBI</td>
</tr>
<tr>
<td>Appt. to surgeon made</td>
<td>Confusion with layout of Doctor office</td>
<td>Rad Oncologist worked together to determine treatment</td>
<td>Home health</td>
<td>Pluses</td>
<td>ACTION – some to explain all ramifications of all meds and procedures</td>
</tr>
<tr>
<td>from Dr. office</td>
<td>MD’s &amp; RN’s – you felt like you knew them when you arrived</td>
<td>Pluses</td>
<td>Social worker</td>
<td>ACTION – determine what things are needed to make pt feel comfortable</td>
<td></td>
</tr>
<tr>
<td>PCP called to talk about diagnosis</td>
<td>Communication between office – coordination of care</td>
<td>Rad Oncology</td>
<td>Social worker</td>
<td>ACTION – determine if counseling is needed and if pt wants it.</td>
<td></td>
</tr>
<tr>
<td>“When you phone this office you will talk to ...”</td>
<td>EBI</td>
<td>Rad Oncology</td>
<td>Social worker</td>
<td>ACTION – have processes in place to facilitate</td>
<td></td>
</tr>
<tr>
<td>EBI</td>
<td>Needed a better understanding of staging of the disease</td>
<td>Rad Oncology</td>
<td>Home treatments</td>
<td>ACTION – talk to all involved to speed up process</td>
<td></td>
</tr>
<tr>
<td>Communication between Drs.</td>
<td>ACTION – get a list of patient’s other doctors</td>
<td>Rad Oncology</td>
<td>Home health</td>
<td>ACTION – talk to all involved to speed up process</td>
<td></td>
</tr>
<tr>
<td>ACTION – Get a list of patient’s other doctors</td>
<td>ACTION – confer with doctors to get an understanding of the stages of cancer</td>
<td>Rad Oncology</td>
<td>Social worker</td>
<td>ACTION – give list to cancer dr and have him/her communicate</td>
<td></td>
</tr>
<tr>
<td>ACTION – Give list to cancer dr and have him/her communicate</td>
<td>Confusion with layout of</td>
<td>Rad Oncology</td>
<td>Social worker</td>
<td>ACTION – give list to cancer dr and have him/her communicate</td>
<td></td>
</tr>
</tbody>
</table>

Pluses:
- Doctor taking time to answer questions
- Physician calling patient at home to check status
- Felt protected by doctor because of communication between physicians
- Liked white board for information on staff
- Financial People Guided them

EBI:
- Needed a better understanding of staging of the disease
- ACTION – confer with doctors to get an understanding of the stages of cancer
- Rad Onc was in Cancer Center location
- ACTION – is it possible to

Pluses:
- Surgeon/Hematologist/
  - Rad Oncologist worked together to determine treatment
  - Tumor Board
  - Clinical Desktop
  - MD’s & RN’s – you felt like you knew them when you arrived
  - Communication between office – coordination of care

EBI:
- If cocktail mix explained better – why/what
- ACTION – explain each drug used and why it’s being used
- Dr. would explain to family and not just expect them to trust he knows what to do
- ACTION – doctors to work on beside manner
- Rad One was in Cancer Center location
- ACTION – give list to cancer dr and have him/her communicate

Pluses:
- Surgeon/Hematologist/
  - Rad Oncologist worked together to determine treatment
  - Tumor Board
  - Clinical Desktop
  - MD’s & RN’s – you felt like you knew them when you arrived
  - Communication between office – coordination of care

EBI:
- Needed a better understanding of staging of the disease
- ACTION – confer with doctors to get an understanding of the stages of cancer
- Rad Onc was in Cancer Center location
- ACTION – is it possible to

Pluses:
- Surgeon/Hematologist/
  - Rad Oncologist worked together to determine treatment
  - Tumor Board
  - Clinical Desktop
  - MD’s & RN’s – you felt like you knew them when you arrived
  - Communication between office – coordination of care

EBI:
- Needed a better understanding of staging of the disease
- ACTION – confer with doctors to get an understanding of the stages of cancer
- Rad Onc was in Cancer Center location
- ACTION – give list to cancer dr and have him/her communicate
<table>
<thead>
<tr>
<th>Action</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Test results, treatment, etc. to other doctors** | Need questions to be answered (how much would you like to know)  
**ACTION** – ask patients if they have any questions  
**ACTION** – get answers for patients  
Appt. to be made for the patient  
**ACTION** – determine what appointments need to be made, who will make them, and notify the patient |
| **Nurse navigator** | Need others to help “hear” the information  
**ACTION** – determine what is expected of a nurse navigator and communicate with the nurse involved |
| **Folder for information** | Help living with uncertainty, questions  
**ACTION** – determine activities that we can do to make patient more acceptable to situation  
Want to feel free to ask doctor questions  
**ACTION** – talk with doctors, make them aware  
**ACTION** – go with patient to speak with doctors  
Allow for more choice in treatment  
**ACTION** – is this realistic? When it comes down to it, relocate?  
If “why” questions would have been answered  
**ACTION** – can doctors take more time with patients when necessary  
Results of x-rays were available before Mon. if done prior to weekend  
**ACTION** – make results more timely  
Could have talked with social worker prior to treatment  
**ACTION** – facilitate interaction with social worker when and if necessary  
Lack of communication between offices-low blood count  
**ACTION** – develop methods for interoffice communication – if not, results could be deadly for patient  
If Rad/Onc was in cancer care center  
**ACTION** – Determine pluses and minuses of moving Rad/Onc  
Nurse Navigator to help get patients for mentoring  
**ACTION** – see if she will help us set up processes  
Pts knew cancer resource ctr was there  
**ACTION** – advertise, make it part of the mentoring process  
Wigs for men  
**ACTION** – research possibilities  
Pts were aware of service/supplies available from Am Cancer Soc  
**ACTION** – research what is available and make it part of the mentoring process  
Holistic therapies for pain, etc. – acupuncture  
**ACTION** – research alternative methods for coping  
Complimentary therapies – message, art, etc., music |
| **Procedures approach** | Continued contact from PFAC mentor to family  
Sympathy cards  
**ACTION** – this is a part of a previous EBI about caring after the patient is cured or deceased – never leave the patient or family hanging  
More info about what to expect on end of life  
**ACTION** – consult with those who have ‘been there’ or the people from hospice |
| Family member wanted more information but was told to stop |
| ACTION – better beside manner needed from doctors, need more understanding between patients and doctors |
| ACTION – meet with doctors, make them aware of this situation |
| I’m going to be alright |
| ACTION – confer with patients and make sure they are in this frame of mind before starting treatment |
| Turnaround time varied between 1 wk to 3 days |
| ACTION – minimize diagnosis time – determine what actions can be taken to get test results back in a timely manner |
| When asked to see surgeon knew something was wrong |
| ACTION – arrange to be with patient when told to see doctor |
| the doctors know best |
| Drs. Not providing same info – doctors need to be educated in caring for whole family |
| ACTION – ensure doctors are united in what they tell the patient |
| ACTION – eliminate patient confusion if it exists |
| No relationship with “new” doctor during crisis situation – do they know my story |
| ACTION – does patient have concern about their past health history? |
| ACTION – enhance communications between patient and doctor |
| No consistency in inpatient care |
| ACTION – determine what inconsistencies exist |
| People thrown in the mix |
| ACTION – if new people enter a patient’s treatment, make sure patient is comfortable with them |
| Folder for information |
| ACTION – design folder for patient’s info |
| ACTION – make this part of previous item |
| E.R. delays – couldn’t contact for hours |
| ACTION – CWI to be involved to streamline processes |
| Better communication between doctor offices |
| ACTION – make one person responsible for all appts and coordinate with pt |
| Consistent processes |
| ACTION – if pt is confused, be the go between to streamline processes |
| Hematology/oncology offices need to streamline processes - herded initially – then sit and wait |
| ACTION – CWI may be able to help us determine how to streamline |
Contact information— Phone number: 314-653-4498 Email address: sjk3344@bjc.org

Patient and Family Advisory Council
The Voice of Patients and Families

WHAT ARE THE GOALS OF THE PATIENT AND FAMILY ADVISORY COUNCIL?
- Improve the flow of information and sharing of knowledge between patients, families and the oncology healthcare team.
- Empower patients, families and staff through continuous education.
- Identify and address patient and family needs in all aspects (body, mind, spirit) throughout the cancer journey.
- Enhance ongoing collaboration and cooperation among clinicians, patients and families for the benefit of the patient’s healthcare team (e.g. primary care doctor, consults, specialists).
- Protect the patient’s dignity and assure safety.
- Assure the best possible medical and emotional outcome for the patient and their family members.
- Participate in the development and planning of patient and family satisfaction initiatives, new facilities and facility renovation.

HOW TO CONTACT US
If you are interested in learning more about becoming a member of the Patient and Family Advisory Council, you can contact Sandi Kenkel, Manager of Radiation/Oncology and PFAC coordinator (by email at sjk3344@bjc.org — or by telephone at 314-653-4498)

Christian Hospital Cancer Care Center

Patient and Family Advisory Council
The Voice of Patients and Families

Contact information—
Phone number: 314-653-4498
Email address: sjk3344@bjc.org
WE INVITE YOU TO BE A PART OF OUR PATIENT AND FAMILY ADVISORY COUNCIL

Enhancing the patient experience is about focusing on healthcare through the eyes of others. We request your partnership and invite you to join our new Patient and Family Advisory Council (PFAC). The rewards of participating on the PFAC will be many, from meeting new friends to hearing the voice of others, and making an impact on the care of the cancer and infusion patients. It’s your opportunity to make a difference and to celebrate hope and healing.

Mission: The Patient and Family Advisory Council for Christian Hospital Cancer Center ensures that patients have a voice in their own cancer journey. We will accomplish this by strengthening communication to:

- Create a partnership with patients, family members and the healthcare team to provide excellence in prevention, treatment, education and research
- Promote integration of care and services
- Provide access to cancer related information, education and support to minimize apprehension and fear.

Our mission statement was created by a dedicated group of patients, family members and staff who met weekly to discuss the formation of the Patient and Family Advisory Council.

What Does Being on the Advisory Council Mean?

The PFAC will be comprised of patients and family members, Christian Hospital leadership and Cancer Center staff. Together we can plan and develop truly responsive services.

We are looking for patients and family members willing to make a commitment to:

- Meet monthly with—Cancer Center leadership, physicians and staff
- Work as a team
- Share experiences
- Provide honest feedback
- Respect the perspective of others
- Meet with other patients and families
- Work on program development projects and other projects outside the monthly meeting
- Educate the leadership and staff
- Work to enhance the patient and family experience
- Transform cancer care

What will be the Time Commitment?

- Participation in monthly meetings (approx. 2 hours each month)
- Attendance at PFAC orientation programs
- An opportunity to engage in additional work outside the meetings for program development and to meet with patients and families about their experiences
Creating a Vision/Mission Statement

**Definition of a vision statement:**
A vision statement is a vivid idealized description that inspires, energizes and helps you create a mental picture of your group. A vision statement is really a picture of the Patient and Family Advisory Council in the future. Your vision statement is your inspiration, the framework for your strategic planning.

Most powerful vision statements generally invoke, involve, and energize people throughout the group. It gives them higher causes to rally behind, feel engaged by and see that what they are doing is worthy. It gives a sense of purpose so group sees itself as “building a cathedral” rather than “laying stones”.

**Definition of a mission statement:**
A mission statement is a brief description of the Patient and Family Advisory Council’s fundamental purpose. A mission statement answers the question, “Why do we exist?”

The difference between a mission statement and a vision statement is that a mission statement focuses on a present state while a vision statement focuses on the future.

Unlike the mission statement, a vision statement is an internal document used for motivation for the members of the Patient and Family Advisory Council.

The See, Hear, Feel tool in the Change Management section is a great tool to use for the development of your vision statement.

Describe your vision statement in present tense as if you were reporting what you actually see, hear, think, and feel after your ideal outcome was realized.
Sample Vision Statements

1. Five years from now, Paula’s will be rated as a “five star” restaurant in the Greater Toronto area by consistently providing the combination of perfectly prepared food and outstanding service that creates an extraordinary dining experience.

2. Within the next five years, the Women’s Center will have helped create a safe, more harmonious community by helping women acquire the education, skills, and resources necessary to build self-sufficient prosperous lives.

3. Within the next five years, Metromanage.com will become a leading provider of management software to North American small businesses by providing customizable, user-friendly software scaled to small business needs.

4. To be a revolutionary leader in raising the standard of excellence for cancer care. Together we will make the vision a PFAC reality.

5. Maximizing outcomes for patients and families through collaboration and teamwork.

6. To be the transformational force in the evolution and advancement of compassionate community-based cancer care.

7. To be a Center of Excellence delivering the highest standard of cancer care providing the utmost confidence in our patients, family members, the community and the healthcare team.
Sample Mission Statements

Adult Patient and Family Advisory Council
Dana-Farber/Brigham and Women’s Cancer Center

*The Dana-Farber/Brigham and Women’s Cancer Center Adult Patient and Family Advisory Council is dedicated to assuring the delivery of the highest standard of comprehensive and compassionate health care.*

Patient and Family Resource Center
University of North Carolina – Comprehensive Cancer Center

*Our mission is to provide information, education, and support to enable our patients and their families to participate fully in all decisions related to the diagnosis of cancer and assist them in better understanding their illness and its impact on their lives.*

Kreamer Family Resource Center
Children’s Mercy Hospitals & Clinics – Kansas City, MO

*The Kreamer Family Resource Center provides families with consumer health information in an effort to help them understand and cope with hospitalization, illness, injury, disability, and family issues, as well as to promote wellness and prevention of injury or illness in children and adolescents. The Family Resource Center also provides recreational and homework support materials for children at Children’s Mercy Hospital. The Kreamer Family Resource Center is open to the community.*

Moffitt Cancer Center
Tampa, Florida

*The Patient & Family Advisory Program is dedicated to strengthening collaboration between patients and family members and the health care team so as to enhance the Cancer Center’s ability to deliver the highest standard of safe, comprehensive and compassionate health care.*

The Heart Center
Massachusetts General Hospital

*The Heart Center Patient and Family Advisory Council insures that voices of patients and families are represented in a multidisciplinary effort to enhance their entire care experience.*
Missouri Baptist Medical Center – Cancer Center Patient and Family Advisory Council

Bylaws

Name: The MBMC Cancer and Infusion Center Patient and Family Advisory Council

I. Mission: The Patient and Family Advisory Council (PFAC) will be a true partner with the MBMC Cancer Center team, involved in decision-making, and committed to creating an environment of safety, dignity, respect, and honesty, to assure the very best for patients and families

II. Vision: To be a revolutionary leader in raising the standard of excellence for cancer care

III. PFAC Goals

1. Create a patient and family centered environment which promotes the best possible medical and emotional outcomes for patients and family members.
   - To enhance communication between patients, family members and the cancer center team
   - Empower patients, family members and staff through continuous education
   - To identify and address patient and family needs in all aspects (body, mind, spirit) throughout the cancer journey.
   - Promote the best possible medical and emotional outcomes for patients and family members
   - Develop list of resources/menu for transition services/facilitate the development of a transition process
     a. Help Maintain connection with patients that have transitioned from the CC.
   - communication of this list. Smooth and unscary as possible; unknowns

IV. Structure

The PFAC membership will consist of the following:

A. Terms – 2 Year terms with Emeritus status. First group of council members will rotate off in May, September or Jan. Then any new members that come on will be asked for a 2 year commitment.

B. Up to 15 patients and or family members
   1. Diverse representation – age, sex, cultural background, race, diagnosis, treatment stage
   2. Must have been or currently treated in new Cancer Center or Sunset Hills
   3. Mix of active patients and those in survivorship or follow up status
   4. At least one patient who has or is being treated at Sunset Hills
   5. Will try to recruit members who have experienced care at facilities outside the BJC network

C. Active members – Any member who has attended four monthly PFAC meetings within a 6 month period
Missouri Baptist Medical Center – Cancer Center Patient and Family Advisory Council
Bylaws

1. Minutes will be circulated to each active member. All PFAC correspondence and documents can be reviewed by members upon request.
2. Each active member has voting privileges

D. Inactive members – Any member who is unable to attend four meetings within 6 months. Voting privileges will be terminated, while distribution of the literature will be continued.
   1. Inactive status can be terminated if after one year the member chooses to no longer be affiliated with the PFAC or chooses to reinstate to active status by attending four consecutive PFAC meetings within a six month period.

E. Hospital Liaison – Liaisons are hospital employees who are assigned the responsibility of providing the link in communication between the hospital and the PFAC and offer support as needed. They will have voting privileges.

F. Meeting facilitator – Recommendation is made for initially the PFAC to have an outside facilitator. Outside is defined as someone who does not work in the MBMC Cancer Infusion Center or does not indirectly or directly report to the Director of Oncology Services.

G. MBMC membership
   1. Seven MBMC members represented on the PFAC
      - One VP
      - Oncology Services Director and or Manager
      - Physician representative (s)
      - Treatment room supervisor
      - Radiation Therapist
      - Hospital liaison to PFAC – Social Worker
      - Rotating staff member

V. Officers
   The Council will revisit the patient/family member chairperson concept at the one year anniversary in May of 09.
   A. Chairperson
      1. Preside over meetings.
      2. Official spokesperson for PFAC
      3. Welcome new members
   B. Co Chair

VI. Procedures
   A. Quorum
   B. Voting
   C. Meetings- the PFAC will meet monthly.
   D. Agenda
E. Bylaws
   1. Amendments to the bylaws will be presented at one meeting and voted on at the following regular meeting.
   2. The bylaws may be amended by majority vote (51%), provided 50% of the active members are in attendance.
   3. All bylaw amendments are subject to MBMC Administrative approval.

F. Complaints/Grievances with the PFAC – Any member who has a complaint regarding PFAC issues should follow these procedures:
   1. Contact any officer or staff liaison to inform them of the nature of the problems and attempt to resolve the issue
   2. Unresolved issues will be presented for discussion and resolution at the next monthly PFAC meeting.

VII. Planning, Reporting, Evaluation
    A. Annual plan – The PFAC will develop an annual plan to include goals and objectives. This will be written by the chairperson and liaison with input from the PFAC members.
    B. PFAC report to Cancer Center leadership or Cancer Center Committee – A member of the PFAC will report to the MBMC Leadership Team on a semi-annual basis.
    C. Annual report on effectiveness of PFAC activities will also be prepared and distributed by the chairperson and staff liaison with the assistance of the PFAC members and MBMC Leadership Team
    D. Minute distribution – minutes will be kept of all PFAC and committee meetings and will be distributed to appropriate parties for review and consideration.

VIII. Guidelines for Authority: The PFAC has the authority given it by the Administration of MBMC. Events organized by the PFAC and the statements issued by the PFAC on behalf of MBMC Cancer Infusion Center are done so with prior approval of the MBMC Administration

IX. Confidentiality
    A. To maintain appropriate and confidential handling of the personal information, no MBMC patient and or family member will be discussed by name in PFAC meetings.
    B. All PFAC members will sign a confidentiality statement that pertains to any MBMC data or patient and family member information.
June 2, 2009

Name
Street
City, State  Zip

Dear Name,

Thank you for volunteering to be a member of the Barnes-Jewish St. Peters Hospital Patient and Family Advisory Council (PFAC) Planning Committee. Through your hard work and dedication, you will play an important role in establishing a committee designed to ensure the voice of the patient and family is the foundation of how we deliver care.

As I mentioned to you on the phone, the PFAC Planning Committee will meet for eight (8) weeks beginning Thursday, June 25 from 5:30 – 7:30 p.m. All meetings will be held in the HealthWise Center located in Professional Office Building #1, 6 Jungermann Circle, Suite 117 located on the hospital campus. HealthWise is your first door on the right after entering the building. Dinner will be provided at every meeting.

I look forward to working with you and the other committee members as we build on our individual strengths to ultimately achieve this success. With your help, we as caregivers, will have a better understanding of the reality of the patients experience and will continue to build on a culture where every decision is made in the best interest of our patient & family. If you have any questions, please contact me at__________.

Sincerely,

PFAC Coordinator
Patient and Family Advisory Council Membership Application
Christian Hospital Cancer Care Center

Today’s Date: ____________

Your Name: ____________________________ Home Address: _____________________
(Please print)

Daytime Phone: (___) _______________ Best Day\ Time To Call: ___________

Email Address: ________________

I am a: _____Patient ________ Family Member

If you are a patient, what is your diagnosis?_________________________

If you are a family member, what is your loved one’s diagnosis?_______________

Tell Us More About Yourself and Your Experience
(Feel free to use a separate piece of paper)

Tell us about your hospital experience (s). What would you have improved about the experience? What impressed you about your experience?

Why do you want to be involved in the Patient and Family Advisory Council?

If you have participated in any organizations or committees, please share some examples:
(These examples may be from work, community, church)
Is there anything else you would like us to know?

Thank you for taking the time to complete this application! Please return this completed form to:

Sandi Kenkel, Manager of Radiation Oncology
Phone 314-653-4498
Email: sjk3344@bjc.org

Before participating in the PFAC you will be asked to sign a confidentiality statement and go thru both volunteer and PFAC orientation.

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<th>Date</th>
<th>Signature</th>
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POSSIBLE INTERVIEW QUESTIONS FOR CANDIDATES ON THE PFAC PLANNING COMMITTEE

1. Tell me a little bit about the services you have used at the hospital.

2. Tell me about a positive experience you have had at the hospital.

3. What are some suggestions you have for improvements?

4. How would you describe someone who uses good listening skills?

5. Why do you think it would be important for a hospital to have a Patient and Family Advisory Council?

6. How have you handled a situation in the past when someone’s background or values were different than yours?

7. Why would you like to be involved in planning a Patient and Family Advisory Council for the Cancer Center?

8. What does “good customer service” mean to you and your family when you use the hospital?
PFAC Orientation Agenda

1. Welcome and Introductions

2. Housekeeping
   - Bathrooms
   - Meeting place and time
   - Parking
   - Meals
   - Who to call-contact sheet (employees/others)
   - Review information in binder

3. Review of Organizational Chart/Roles

4. Discussion of Patient and Family-Centered Care

5. What is a PFAC (what it isn’t)?
   - Explanation of council
   - Building a Partnership
   - Make up of council
   - Structure
   - Member responsibilities

6. Examples of current PFAC’s

7. System Approach to PFAC (MoBap, Christian, St. Peter’s, Children’s)

8. How did we get here?
   - Development of Planning Committee
   - Review of Mission, Vision and Goals
   - Meeting attendance
   - How to prepare for a meeting – what to wear, what to do ahead of time
   - and what to bring

9. Communicating effectively – techniques for getting your message across
   - Telling your story so people listen
   - How to ask tough questions
   - What to do when you don’t agree
   - Listening to and learning from other’s viewpoint
   - Thinking beyond you own experience

10. View 13-minute Patient and Family-Centered Care video

11. Tour of inpatient unit, Infusion Center and Radiation/Oncology Center (CH only)

12. Open discussion about what a PFAC could be for this hospital
Things included in binder for each PFAC member-

- Hospital specific Cancer Center Info
- PFAC Presentation
- Website of interest
- Bylaws
- Articles (Wall Street Journal, Trustee, “Making Patient-Centered Care Come Alive”)
- Notes
- Contact sheet
Prepare for First Advisory Council Meeting

It is important to take the time to prepare for the first meeting with your Patient and Family Advisory Council. This will be their first impression of the PFAC process and your openness to partnering with patients and families. Allow time at the first meeting for members to start building relationships. This can be through a structured activity or just providing for time to socialize.

Discussing the purpose of the Advisory Council and their roles as members is also important. One way to demonstrate commitment from your organization is to have the senior leadership address the council members and explain the benefits they see from the council.

Reviewing the mission, vision and goals developed by the planning committee can provide the council members with a sense of direction. Sharing the background work to start the council can help members understand the role of the council (a sample agenda is located in the attached sections).

It will also be important to coordinate the logistics for the meeting so that it runs smoothly. Securing a room that will meet the needs of the group is a priority, including room for flip charts with a screen and projector. Most meetings are held in the early evening with dinner provided. Someone will need to make arrangements for food or refreshments. A rule of thumb for coordination of meetings indicates that the time you need for planning should be double the time of the meeting.

LESSONS LEARNED: INITIATE PHASE

- The PFAC members must be seen as full partners in the decision-making process.
- Senior leadership must be involved and visible to PFAC members.
- Department or service line staff members must create an awareness of the need for PFAC input (e.g. selected staff interviews, process design, rapid improvement event, facility renovations, general decision-making).
- Set-up council for quick wins; initial projects should be readily achievable.
- Bring ideas to the council that are in rough form and not “fully baked”.

# Initiate Phase Checklist

<table>
<thead>
<tr>
<th>Activity</th>
<th>Owner</th>
<th>Target Date</th>
<th>Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prepare agenda for first meeting.</td>
<td></td>
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</tr>
<tr>
<td>Create binder for PFAC members to include hospital specific information - PFAC presentation, websites, bylaws, articles, contact numbers, and notes.</td>
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<tr>
<td>Create time for socialization during first meeting, plan for icebreaker activity.</td>
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<tr>
<td>Determine food to be provide and order food.</td>
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<tr>
<td>Schedule meeting room.</td>
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<tr>
<td>Set reminder letter to PFAC members indicating room location, time and date of meeting.</td>
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<tr>
<td>Prepare patient and family-centered information to review at meeting (articles, video).</td>
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<tr>
<td>Share mission, vision and goals for PFAC.</td>
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<tr>
<td>Allow time for members to share stories and burning issues.</td>
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<tr>
<td>Review the work completed by the planning committee.</td>
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<tr>
<td>Discuss plans for future meetings to encourage participant engagement.</td>
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<tr>
<td>Facilitate group through patient journey - identify positive/negative experiences.</td>
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<tr>
<td>Select patient/family member as chair or co-chair.</td>
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</tr>
<tr>
<td>Invite representatives from another PFAC to share experience and lessons learned.</td>
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</tbody>
</table>
Patient and Family Advisory Council
Christian Hospital Cancer Care Center
Team Meeting

Date: September 17, 2008
Time: 5:00 – 7:30 pm
Location: Conference room A

Purpose: To meet each other and learn about our roles as Advisory Council Members and participate in volunteer orientation.

Desired Outcomes: By the end of this meeting, we will have:

- Introduced and meet the CH leadership and members of the Advisory Council
- Learned about responsibilities as a hospital volunteer
- Provided framework for the Patient and Family Advisory Council

<table>
<thead>
<tr>
<th>Topic / Content</th>
<th>Who</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome and Introductions</td>
<td>Laurie Brown, Ron McMullen, Dr. Hannah Ha, Gay Cunningham, Risë Schreiber</td>
<td>30 mins. 5:00 – 5:30 pm</td>
</tr>
<tr>
<td>Social Time – Let’s get to know each other</td>
<td>All participants</td>
<td>30 mins 5:30 – 6:00 pm</td>
</tr>
<tr>
<td>Housekeeping Items – Bathrooms, Parking, Meals, Meeting place and time, Review of binder, Family-Centered Care Conference</td>
<td>Sandi Kenkel</td>
<td>15 mins 6:00 – 6:15 pm</td>
</tr>
<tr>
<td>Dinner, CH Overview</td>
<td>All participants, Sandi Kenkel</td>
<td>20 mins 6:15 – 6:35</td>
</tr>
<tr>
<td>Volunteer Orientation</td>
<td>Sandi Kenkel, Laurie Brown</td>
<td>30 mins 6:35 – 7:05 pm</td>
</tr>
<tr>
<td>Overview of Advisory Councils Video, Questions/Discussion</td>
<td>Laurie Brown</td>
<td>20 mins 7:05 – 7:25 pm</td>
</tr>
</tbody>
</table>

Meeting close:
- Next Steps
- Agenda for next meeting
- Explanation of + / EBI
- Thanks!

5 min 7:25 – 7:30 pm

This GROPER/GOACT template is found on Transformation Station at http://bjcnetnew.carenet.org/sites/LeanSigmaTransformationStation/default.aspx
**Purpose:** To learn about role as Advisory Council members

**Desired Outcomes:** By the end of this meeting, we will have:
- Listened to a report from Family-Centered Care Conference
- Provide framework for Patient and Family Advisory Council
- Brainstorm improvement activities

<table>
<thead>
<tr>
<th>Topic / Content</th>
<th>Who</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dinner and Welcome</td>
<td>Laurie Brown</td>
<td>15 mins</td>
</tr>
<tr>
<td>Introductions (Ginny to give Skunk info Now)</td>
<td>Sandi Kenkel</td>
<td>5:00 – 5:15 pm</td>
</tr>
<tr>
<td>Celebrations (Article in BJC Today - Vernetta)</td>
<td>Risë Schreiber</td>
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<tr>
<td>Report from Family Centered Care Conference</td>
<td>Carolyn Stokes</td>
<td>15 mins</td>
</tr>
<tr>
<td>Hand out books</td>
<td>Kim Predmore</td>
<td>5:15 – 5:30 pm</td>
</tr>
<tr>
<td>Development of Operating Agreement</td>
<td>Sandi Kenkel</td>
<td>5 mins.</td>
</tr>
<tr>
<td>SDK, acronyms, Misery is optional</td>
<td></td>
<td>5:30 – 5:35 pm</td>
</tr>
<tr>
<td>Review of Agenda</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overview of Patient and Family Advisory</td>
<td>Laurie Brown</td>
<td>30 mins</td>
</tr>
<tr>
<td>Councils</td>
<td></td>
<td>5:35 – 6:05 pm</td>
</tr>
<tr>
<td>American Hospital Association Video</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient and Family-Centered Care – Partnership for Quality and Safety</td>
<td>Laurie Brown</td>
<td>30 mins</td>
</tr>
<tr>
<td>Review of Bylaws – Action item</td>
<td>Sandi Kenkel</td>
<td>25 mins</td>
</tr>
<tr>
<td>Burning Issues</td>
<td>Laurie Brown</td>
<td>20 mins</td>
</tr>
<tr>
<td>Navigator</td>
<td></td>
<td>6:05 – 6:30 pm</td>
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<tr>
<td>Folder</td>
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<tr>
<td>Mentor</td>
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<tr>
<td>Transition from Cancer Center</td>
<td></td>
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<tr>
<td>Other Opportunities (CWI)</td>
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</tr>
</tbody>
</table>

This GROUPER/GOACT template is found on Transformation Station at http://bjcnetnew.carenet.org/sites/LeanSigmaTransformationStation/default.aspx
SUSTAINING THE PATIENT AND FAMILY ADVISORY COUNCIL

Sustaining the Council

Tips for sustaining a healthy PFAC:

- Set priorities and focus efforts on meaningful collaborative projects.
- Devote time to planning and evaluation of council efforts.
- Maintain continued engagement and support of hospital leadership.
- Create a balance between new members and committed members with longevity of service.
- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- Ensure that the council is representative of the patients served.
- Invest in building the talents of the members.
- Set and achieve measurable goals.
- Track accomplishments and provide positive feedback.
- Assign council members to other hospital committees.
- Consider having a “patient and family leave policy” when illness demands might interfere with council meetings.
- Create a variety of way for patients and families to participate in the consideration of issues (e.g. conference calls, written review of materials).
- Develop a support network through participation in the BJC PFAC Consortium.
- Empower open communication; avoid the temptation to defend current processes.

Current List of PFAC Accomplishments:

- Providing patient and family perspective to the Clinical Workflow Initiative for the Community Hospitals.
- Creating a resource folder for the cancer patients.
- Council members work as volunteers at the Cancer Center to orient patients and families.
- Development of PFAC website.
- Family involvement with teaching and mentoring.
- Assistance with signage and wayfinding.
- Providing feedback to marketing on brochures and mailings.
“We are committed, passionate and “trained” advocates for patients, families, staff and community – based healthcare.”
PFA Patient

“Any discussion on improving patient care must have patient and family involvement. If it doesn’t, you are missing a voice.”
PFA Patient

“We have jelled as a group and we look forward to these meetings. We know the hospital is backing our efforts and that means everything to us.”
PFA Family Member

“If just one person’s cancer journey is benefited, it will be a priceless contribution. I hope the Patient and Family Advisory Council simply diminish some of the fear and lack of control that is so intense when a cancer diagnosis stun’s one’s world.”
RN, Oncology

“This council is very important to this hospitals’ future by involving patients, family members and the healthcare team before, during and after treatment. I am proud and honored to have been a part of creating the Patient and Family Advisory Council.”
Care Tech, Outpatient Oncology

“I think PFAC is the most interesting and thought provoking committee I attend. I leave each meeting stimulated to how I can do things better as a physician and how we can do things better as a cancer center.”
Physician on PFAC
Agenda Request
Patient and Family Advisory Council

Agenda Subject: _________________________________________________

Presenter: __________________________    Phone Number:______________

Time Requested:_____________________     Meeting Date Requested:_______

Short Summary of the Subject:

Issues Related to the Subject:

Support and or Action Requested By the Council:

Council Member Request____________________________

Date Submitted               _______________________________

Approved    OR   Not At This Time ( Circle One)

If Approved, PFAC meeting date for presentation_____________________


SURVEY FOR PFAC PRESENTERS

Thank you for your presentation to and request for input from our Patient and Family Advisory Council (PFAC). We would greatly appreciate your feedback on this process, and how well it has worked for you.

Please take time to complete this brief survey.

Name ______________________________________________________________

Subject of presentation ________________________________________________

Date ( month/year) of presentation ______________________________________

<table>
<thead>
<tr>
<th>Highly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Highly Disagree</th>
<th>N/A</th>
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<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Please answer the following:

1. There was sufficient time allotted for my presentation.  
2. There was sufficient time allotted for feedback/discussion.
3. I have used or plan to use the input/recommendations from the PFAC.
4. I believe the input from the PFAC will result in creating a more efficient and effective outcome of the project/process presented.
5. The PFAC is a valuable asset to hospital.
6. I would bring other projects/issues to the PFAC for their input.

Additional Comments/Suggestions  __________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
The Patient and Family Advisory Consortium is composed of representatives from the Patient and Family Advisory Councils at the BJC Community Hospitals.

This group meets quarterly to share ideas and discuss ways to work together. This is a great way to network with others with a goal to work together to be partners in healthcare with patient and families.
CONTACT INFORMATION FOR BJC HEALTH SYSTEM
PATIENT AND FAMILY ADVISORY COUNCILS

Barnes Jewish St. Peters Hospital

Siteman Cancer Center
Sharon Lee
Manager, Cancer and Women’s Center
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Phone: 636-916-9026

Christian Hospital – Cancer Center

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Phone: 214-653-4498

St. Louis Children’s Hospital

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Ann McCarthy
Email: AMccarthy@bjc.org

Missouri Baptist Medical Center

Cancer Center
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Phone: 314-996-5669

Inpatient Services:
Susan Smith
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Email: sks3087@bjc.org
Phone: 314-996-4367

The Siteman Cancer Center
Barnes-Jewish Hospital

JoAnn O’Neill
Service and Quality Specialist
Email: jao2841@bjc.org
Phone: 314-454-8051

Tara Hendrix
Operations Specialist
Email: txh0086@bjc.org
Phone: 314-454-8633
WEBSITES

http://www.familycenteredcare.org/ - Institute for Family Center Care

http://www.ihi.org/ihi - Institute for Healthcare Improvement

http://www.dana-farber.org/pat/pfac/adult-advisory/default.html - Dana Farber Cancer Institute Patient and Family Advisory Council

http://www.planetree.org – Planetree Hospital

http://www.pickereurope.org – The Picker Institute

http://www.iom.edu – Institute of Medicine

http://www.joiseking.org – Josie King Foundation

http://www.voice4patients.com – Voice for Patients

http://www.aha.org – The American Hospital Association


http://www.commonwealthfund.org/topics/topics_list.htm?attrib_id=15313 – The Commonwealth Fund

http://cincinnatichildrens.org – Cincinnati Children’s Hospital

http://patientsafety.org – Consumer’s Advancing Patient Safety

13-minute video on patient and family-centered care – American Hospital Association

http://mailman.listserve.com/listmanager/listinfo/pfacnetwork - PFAC listserv
<table>
<thead>
<tr>
<th>Tool/Samples</th>
<th>Section</th>
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</thead>
<tbody>
<tr>
<td>Agenda Request</td>
<td>Sustain</td>
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<td>Bibliography</td>
<td>Resources</td>
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<tr>
<td>Brochures</td>
<td>Planning</td>
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<td>Budget</td>
<td>Introduction</td>
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<tr>
<td>Bylaws</td>
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<td>Change Management Tools</td>
<td>Pre-planning</td>
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<td>Charter</td>
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<tr>
<td>Contact List</td>
<td>Resources</td>
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<tr>
<td>Ice Breaker Exercise</td>
<td>Initiate</td>
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<tr>
<td>Letter to Planning Committee Members</td>
<td>Planning</td>
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<tr>
<td>Mission Statements</td>
<td>Planning</td>
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<tr>
<td>Organizational Structure</td>
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<tr>
<td>Patient and Family-Centered Video (AHA)</td>
<td>Resource</td>
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<tr>
<td>Patient Journey</td>
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<td>Planning Committee Agenda</td>
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<td>Planning Committee Presentation</td>
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<td>Planning Committee Timeline</td>
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<td>PFAC Agenda (first meeting)</td>
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<td>PFAC Application</td>
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<td>PFAC Consortium Flyer</td>
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<td>PFAC Listserve</td>
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