



Oncology Roundtable

Cancer Patient and Family Advisory Council Toolkit

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Cancer Patient and Family Advisory Council (PFAC) Toolkit

Overview:

This tool equips cancer centers to establish or reinvigorate an active Patient and Family Advisory Council (PFAC). The purpose of a PFAC is to capture the unique perspective of current and former patients and their families on cancer center processes and initiatives to ensure a patient-centered focus and positively impact the patient experience. In addition, the council enables current and former patients to offer their input and perspective on hospital initiatives and work on improvement projects that are personally meaningful. This tool provides step-by-step guidance on creating a PFAC, including: creating an effective committee structure, recruiting former patients/family members and current staff to serve on the committee, and ensuring patient and family advisors remain committed and engaged. The significant up-front time investment required to set up and establish a PFAC drastically minimizes the potential for utilization and organization issues down the line.

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Source: Oncology Roundtable interviews and analysis.

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Step 1: Define Commitments

While the PFAC members¹ themselves will customize each individual, estimate the time commitment associated with their commitment; for example, how often meetings will be held, when the PFAC will meet, and how long term limits will be. (The Oncology Roundtable recommends at least quarterly meetings, but preferably monthly, and membership terms be of one or two years to ensure the PFAC represents current hospital experiences.) These commitments should be outlined in a bylaws draft that will later be ratified by the entire council.

Step 2: Determine PFAC Stipend

Work with the appropriate team of individuals, including finance staff, to determine if you can offer a small stipend to PFAC volunteers (even if just enough to cover travel expenses and parking). Determine the available amount so you can communicate it to former patients and family members as you recruit them.

Step 3: Recruit PFAC Members

A broad-based approach to recruiting PFAC members will draw a more diverse pool of applicants. Current staff, former patients, and family members of previous patients are all candidates for PFAC membership.

A. Ask Managers for Former Patient Recommendations for the PFAC:

Email all unit managers to ask for a list of names of patients who have stayed on their units within the past year who would be interested in PFAC participation. Encourage managers to reach out to frontline staff directly for their recommendations as well.

B. Recruit Current Volunteers as PFAC Candidates:

Recruit former patients currently volunteering in other capacities within the cancer center to join the PFAC. Work with the director of volunteer services to determine who might be a good fit. Provide the individuals with fliers for the information session and applications to the PFAC.

C. Send Letter and Application to PFAC Candidates:

Send a letter notifying former patients of upcoming PFAC information sessions and application to join the PFAC. The Oncology Roundtable recommends initial outreach details include the estimated time commitment asked of patients.

D. Recruit Hospital Staff to the PFAC:

The Oncology Roundtable recommends each PFAC include at least one hospital staff member (ideally three or four) in addition to the creator to ensure that council conversations reflect both the patient and staff perspective. To recruit staff to participate, email unit managers and ask them to inform their staff of the opportunity to volunteer with the PFAC.

You may provide them with the following talking points:

- The new Patient and Family Advisory Council is looking for a few staff representatives.
- The goal of the PFAC is to capture the unique perspective of current and former patients (and their families) on cancer center processes and initiatives to ensure a patient-centered focus and positively impact the patient experience.
- The role of staff members will be to provide balanced perspective at each of the meetings and help assess the feasibility of new project ideas based on their understanding of hospital operations and realities.
- Monthly PFAC meetings will provide a unique insight into the patient perspective as well as cancer center projects and priorities

1) The terms "PFAC members" and "PFAC advisors" will be used interchangeably throughout this tool.

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Sample Application

DANA-FARBER/BRIGHAM AND WOMEN'S



Dana Farber/Brigham and Women's Cancer Center's Adult Patient & Family Advisory Council

Thank you for your interest in joining the Adult Patient and Family Advisory Councils (APFAC). The APFAC is dedicated to assuring the delivery of the highest standards of comprehensive and compassionate health care provided by Dana-Farber/Brigham and Women's Cancer Center. Working in active partnership throughout the Institute, the Council strengthens communication and collaboration among patients, families, caregivers and staff; promotes patient and family advocacy and involvement; and proposes and participates in the development and evaluation of oncology programs, services, and policies.

If you are a patient or family member of a person treated at Dana-Farber/Brigham and Women's Cancer Center, you are eligible to apply for Adult PFAC membership.

Membership requires a minimum of a one-year commitment (renewable for six years), attendance at monthly Council meetings and participation on a minimum of two committees, task forces or special projects.

Application Process

Prospective applicants are required to complete the attached membership application. Please include the following information with the application:

- A current resume, curriculum vitae, or biographical statement outlining personal, professional and volunteer experience; and
- An interest statement including, but not limited to, the following information:
 - why you are interested in Council membership
 - what patient advocacy means to you
 - why you believe you will be an advocate for patient- and family-care
 - what qualities and skills you will contribute to the Council
 - the amount of time you are able to commit to Council work
 - examples of your experience of group membership (if applicable)

Please return the completed application and required documents via US Postal Service, email or fax to: Patient and Family Advisory Council Office, Dana-Farber Cancer Institute, 450 Brookline Avenue, YC-151, Boston, MA 02215, pfac@dfci.harvard.edu or fax # 617-632-4099. If you have any questions, you may contact the PFACs office via telephone at (617) 632-4319 or via email.

Applications are reviewed upon receipt. Potential members are contacted for on-site interviews with staff and Council members. Accepted applicants must complete health screening requirements (including documentation of vaccine history and a TB test) and attend an on-site Volunteer and PFAC orientation.

Source: Dana Farber Cancer Institute, available at: <http://www.dana-farber.org/uploadedFiles/Library/how-to-help/get-involved/volunteer/how-to-apply/adult-pfac-membership-application.pdf>, last accessed May 2013; Oncology Roundtable interviews and analysis.

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Sample Application (cont.)

DANA-FARBER/BRIGHAM AND WOMEN'S



Dana Farber/Brigham and Women's Cancer Center's Adult Patient & Family Advisory Council

Section One:

Name _____
Address _____
Telephone _____ *Please indicate preferred phone number and best time to reach you*
Work _____ Home _____ Cell _____
Email address _____

Are you eligible to work in the United States of America? Yes ___ or No ___

Section Two:

Please indicate to which Council you are applying:

___ Adult patient currently in treatment ___ Family member of adult patient currently in treatment
___ Adult cancer survivor ___ Family member of adult cancer survivor
___ Bereaved family member ___ If family member, relationship to patient: _____

Section Three:

Patient Diagnosis (type of cancer) _____ Patient age at diagnosis _____
Year of original diagnosis _____ Year treatment was completed (if applicable) _____
What did your/your family member's care involve? Please check all that apply:

___ Chemotherapy ___ Radiation Therapy ___ Surgery ___ Nutritional Counseling
___ Integrative Therapies (massage, reiki, acupuncture) ___ Speech & Swallow Counseling
___ Spiritual Services ___ Other (please specify) _____

Section Four:

Your area of interest, please check all that apply:

___ Outpatient Care ___ Clinical Research & Trials ___ Communication, Marketing & Public Relations
___ Inpatient Care ___ Patient Safety & Quality Improvement
___ Supportive Resources & Services

Conditions of Volunteer Services

Please read before signing

I certify that the statements made in this application are true and correct and have been given voluntarily. I understand that I will not be paid for my services as a volunteer member of the Council. I agree to abide by the guidelines of Volunteer Services, to respect patient confidentiality, and to uphold the traditions and standards of Dana-Farber Cancer Institute. I understand that membership on the Adult Council will be based upon approval from Volunteer Services, Occupational Health Services, Council members and the director of Volunteer Services and the Shapiro Center for Patients and Families. By signing this application, I am authorizing the staff of the Advisory Council to discuss my participation in the program with my, or my family member's clinical care staff, including physician, nurses, social works or other psychological providers.

Source: Dana Farber Cancer Institute, available at: <http://www.dana-farber.org/uploadedFiles/Library/how-to-help/get-involved/volunteer/how-to-apply/adult-pfac-membership-application.pdf>, last accessed May 2013; Oncology Roundtable interviews and analysis.

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Sample Application (cont.)

DANA-FARBER/BRIGHAM AND WOMEN'S



Dana Farber/Brigham and Women's Cancer Center's Adult Patient & Family Advisory Council

Volunteers will demonstrate a readiness to help others, maintain respect for collaboration and assist DFC in delivering quality patient and family cancer care.

I understand that membership on the Council requires my commitment to attend monthly Council meetings and to participate on committees, task forces and/or special projects throughout my term. Membership terms are one-year in length and may be renewed for a maximum of three terms.

Applicant signature/date: _____

For those applying as a family member: In order to assure compliance with the Federal HIPAA regulations, family members must include the patient's name and obtain his/her signature to indicate that he/she understands you may use his/her name and/or medical history information in your capacity as Council members.

Patient name: _____

If applicable, patient signature/date: _____

Source: Dana Farber Cancer Institute, available at: <http://www.dana-farber.org/uploadedFiles/Library/how-to-help/get-involved/volunteer/how-to-apply/adult-pfac-membership-application.pdf>, last accessed May 2013; Oncology Roundtable interviews and analysis.

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Step 4: Hold an Information Session for PFAC Candidates

The purpose of an information session is to further describe the council, outline member expectations, generate interest in applying for the PFAC, and answer question of potential applicants.

A. Remind PFAC Candidates of Information Session:

Reach out to the current and former patients who responded to your recruitment efforts through their preferred method of communication (phone, email, etc.). Remind them of the upcoming information session and share an additional copy of the application. Give them the option of submitting it via email ahead of time or bringing it to the information session.

B. Discuss Impetus for PFAC Creation:

Discuss the impetus for the PFAC's creation and goals for the committee. Recommended goals for PFAC members include: asking interested members to weigh in on improvement projects informed by their own hospital experience, asking PFAC members to formally serve on cancer center committees and share the patient perspective on committee initiatives, and assigning PFAC members to cancer center projects that have requested PFAC feedback.

C. Distribute and Collect Completed Applications:

Ensure that each interested PFAC candidate completes an application and submits it to the information session leader.

D. Describe Next Steps:

Let the potential patient advisors know you will reach out to them directly to schedule an interview to determine if they would be a good fit for the PFAC.

Step 5: Further Screen Recruits OR Bolster Recruitment Efforts

If turnout to your information session is robust and you receive more than 30 applications, narrow the candidate pool through an interview process to select between 10 and 20 final qualified advisors. To screen candidates and narrow the applicant pool to only those individuals most suited to serve as advisors, conduct an in-person or phone interview with each candidate individually, using the questions below.

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Step 5: Further Screen Recruits *OR* Bolster Recruitment Efforts (cont.)



Question	What to Look for in the Response	Red Flags
Tell me about your experience as a patient in the cancer center.	<ul style="list-style-type: none"> Thoughtful recounting of story Comfort with telling one's story 	<ul style="list-style-type: none"> Individual too emotional to convey story Individual harbors anger or hostility toward hospital he or she cannot look past
Why do you want to be an advisor?	<ul style="list-style-type: none"> Desire to improve the patient experience for others Certain experience left an impression (positive or negative) but motivated to change it for the better for other patients Desire to help others Interest in problem solving 	<ul style="list-style-type: none"> Individual seems to hold a grudge or be fixated on negative hospital experience Unable to articulate why he or she would like to be an advisor
What are some things you hope to accomplish as an advisor?	<ul style="list-style-type: none"> Describes at least one concrete, relatively realistic idea for improving the hospital experience 	<ul style="list-style-type: none"> Unable to articulate any concrete aspirations Individual seems already invested in wildly unrealistic goals

If your information session did not yield more than five potential PFAC participants, hold an additional session and continue the recruitment efforts described on the previous pages.

Source: Oncology Roundtable interviews and analysis.

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Step 6: Finalize PFAC Roster and Contact Each Advisor:

After finishing the recruitment process, create your final list of advisors. Email all advisors separately to let them know they have been selected to serve as advisors using a form of the email template below.

Dear Ms. Hite,

It is my great pleasure to inform you that you have been selected as a patient advisor at Macklemore Cancer Center. I am excited to work with you to improve the patient experience. I am in the process of arranging the committee's first meeting. Please respond to this email with the days and times you are generally able to meet for about 1 hour. I will be in touch as soon as I have compiled all of the other members' schedule.

If you have any questions or are no longer able to serve as an advisor on the Patient and Family Advisory Council, please do not hesitate to reach out to me directly.

*All the best,
Gretchen Morgan, Patient and Family Advisory Council Facilitator*

If you do not believe someone would be a suitable addition to the PFAC, try to offer that individual a different type of patient volunteer opportunity. Use the following sample letter as a guide.

Dear Mr. Guetta,

Thank you for your interest in Macklemore Cancer Center's Patient and Family Advisory Council. Unfortunately, we are unable to offer you a spot on the council at this time. We appreciate your generous offer. We were very fortunate to receive many responses to our outreach looking for members, so at this time I'd like to instead offer you an opportunity to ___(volunteer at an event, serve on a separate council, et.)___. If you are interested, please email me directly at GMorgan@MCC.edu.

*All the best,
Gretchen Morgan, Patient and Family Advisory Council Facilitator*

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Step 7: Conduct Inaugural PFAC Member Orientation and Training

Prepare an agenda for the first meeting that covers advisor introductions, general orientation to the PFAC, member expectations, and training on how to effectively communicate in a group. First meeting agenda items should include:

I. Welcome and Meeting Purpose

The introductory portion of the meeting is designed for advisers to get to know each other and become more familiar with the objectives and proceedings of the Patient and Family Advisory Council.

The training portion of this meeting will be used to ratify bylaws, acquaint council members with processes and structures, and discuss effective PFAC member communication skills.

If all topics do not fit into your allotted PFAC meeting time, you may wish to hold two separate sessions: one introductory session and one training session.

II. Group Introductions

Introduce yourself and ask each of the patient and staff council members to introduce themselves and tell their stories (or for staff, why they joined the PFAC).

III. Overview of PFAC Role

Provide context of how the PFAC will support the broader cancer center community and goals. You may wish to cover:

- A. The vision and goals of the cancer center
- B. An overview of the patient- and family-centered care approach to health care
- C. Background of and impetus for the council's creation
- D. The role of the PFAC, and how it can assist the cancer center and overall organization in achieving its vision and goals
 - Make it clear that sometimes the council will have the opportunity to develop its own initiatives, but a large portion of its work will involve providing feedback on established cancer center projects or programs.
 - Cancer center staff are included on the council to provide the informal, process-based perspective and shed light on what may or may not be feasibly implemented in the cancer center.

IV. Explanation of Expectations

- A. Meeting attendance, which will be defined in PFAC bylaws
- B. How meetings are conducted
 - Reaching consensus
 - Approval of minutes
 - "No one speaks while a patient is speaking" policy
 - PFAC feedback request process

Source: Oncology Roundtable interviews and analysis.

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C. How to prepare for a meeting

- What to wear
- What to do ahead of time
- What to bring

D. Determine meeting logistics:

- Find the best time and frequency for the committee to meet (The Oncology Roundtable recommends the PFAC meet at least quarterly, but preferably monthly)
- Announce the date for the next meeting; if possible, hand out a calendar with tentative future meeting dates
- Confirm a standard method that will be used to communicate future meeting details to PFAC advisors

IV. Ratify Bylaws

After discussing committee expectations, ensure the written bylaws reflect the final PFAC decision. Sample bylaws are provided in this toolkit, which you may wish to alter depending on your cancer center's individual PFAC needs. You may wish to have all PFAC advisors sign a copy of the ratified bylaws at a later meeting. Bylaws typically include:

- C. Council mission
- D. Member makeup and requirements
- E. Council officer nominations and duties
- F. Council procedures (bylaw amendments, meeting minutes, feedback request processing, etc.)

VI. Training: How to Be an Effective Council Member

The purpose of PFAC advisor training is to outline ideal tactics of communication both within the council and with external groups. This training sets the expectation that all PFAC feedback and discussions will be conducted in a constructive and respectful manner.

- A. This can be accomplished in group discussion format or through case studies and role-play exercises.



Group Communication Techniques to Cover:

Telling your story so people will listen

How to ask tough questions

What to do when you don't agree

Listening to and learning from others' viewpoints

Thinking beyond your own experience

Source: Oncology Roundtable interviews and analysis.

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Sample Bylaws

Robinson¹ Cancer Center Advisory Council Bylaws

Article I. Mission

The Robinson Cancer Center Advisory Council advises and assists the Robinson Cancer Center in carrying out the Robinson Promise by partnering with leadership to ensure that:

- The well being of the patient, family and care-giver are at the center of all decisions.
- The Cancer Center offers compassionate and holistic care to anyone affected by cancer through the provision of the highest quality clinical and support services.
- The community is aware of, and engaged in, our programs and services.
- Continuing improvements are made to the entire cancer care continuum with the purpose of evolving to meet the needs of our growing community.

Article II. Vision

To support the Cancer Center in becoming the Regional Cancer Referral Center of the Western Metro area.

Article III. Members

Section 1. Eligibility: Patients, family members, caregivers, community members, and Robinson staff are eligible to be members of the council.

Section 2. Council Makeup: The council will be made up of the Director of the Cancer Center, other supporting Cancer Center staff members on an as needed basis and at least 10-12 patients, family members, caregivers and/or community members. A goal of the council makeup will be to have the greatest diversity possible taking into account culture, race, background, age, gender, socio-economic status and geographical location.

Section 3. Membership Term: A term of Active Membership will consist of 1 year, renewable each year for a maximum of 3 years. Individuals will be polled for their preference for continued membership at the end of each year.

Section 4. Leave of Absence/Resignation: Council members may resign or request a Leave of Absence from the Council at any time during their term. A Leave of Absence will be when circumstances require that the member be absent from regular meetings for a period of 3-6 months. (see Article 4, section 3. Attendance)

Section 5. Recruitment: Council members and Robinson staff will be utilized to recruit and recommend future Council members.

Section 6. Selection: Potential new members will be vetted by members of the Cancer Center staff and the Chairperson of the Advisory Council. New members shall be voted in by a 2/3 affirmative vote from the council.

Section 7. Emeritus Members: Council members who have served 3 years may become Emeritus members. They may attend council meetings, and give input, but will not have voting privileges. They may represent the council on special committees and projects.

Section 8. Chairperson: The Chairperson will be a non-Robinson staff member. The Chairperson is responsible for setting Council meeting agendas, conducting meetings, coordinating between council members and staff, and serving on any committees where the Chairperson is specifically requested.

1) Pseudonym.

Source: Oncology Roundtable interviews and analysis.

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Sample Bylaws (cont.)

The Chairperson will be elected by a 2/3 affirmative vote of the Council members. The standard term for a Chairperson will be 2 years.

Should a Chairperson resign or be unable to perform the duties of the position, the Council may choose to elect a replacement to complete the term, or leave the position open until the next scheduled election.

A Chairperson elect may be appointed during the last year of the current Chairperson's term and work with the Chairperson to ensure a smooth transition.

Article IV. Meetings

Section 1. Regular Meetings: Regular meetings may be planned monthly, but will be held at least once per quarter. The time and place will be decided at the convenience of the majority of the Council.

Section 2. Special Meetings: Special meetings may be called by the Council Chair as deemed necessary. Council members will be given at least 48 hours advanced notice of the meeting and the agenda.

Section 3. Attendance: Attendance is important and required. Should a council member miss 2 consecutive meetings, whether it is a regularly-planned or a special-called meeting, their member status will be evaluated by the full council, and may be terminated.

Section 4. Quorum: An official meeting will require the presence of a minimum of 60% of the Council members to be called to order.

Section 5. Minutes/Agenda: Minutes will be kept for all regular/special meetings. A member of the Council will be responsible for recording and distributing the minutes in a timely manner to all Council members after they have been approved. Minutes may be approved and distributed electronically. Approved minutes will be posted within the Wellness Center, Radiation Oncology, and the Infusion Center.

The agenda will be established by the Chair and distributed to the membership 48 hours prior to each meeting. Agenda items may be suggested by any Council member.

Section 6. Special Committees or Projects: The council may decide the need to create a special committee or task force in order to further the work of the Council. Any Council member or Emeritus member may participate.

Section 7. Voting Rights: Each member shall equal one vote. No proxy or substitute will be accepted.

Article V. Amendment Procedure:

These By-laws may be amended at any regular Council meeting (quorum required), by an affirmative vote of 60% of the Council members.

Source: Oncology Roundtable interviews and analysis.

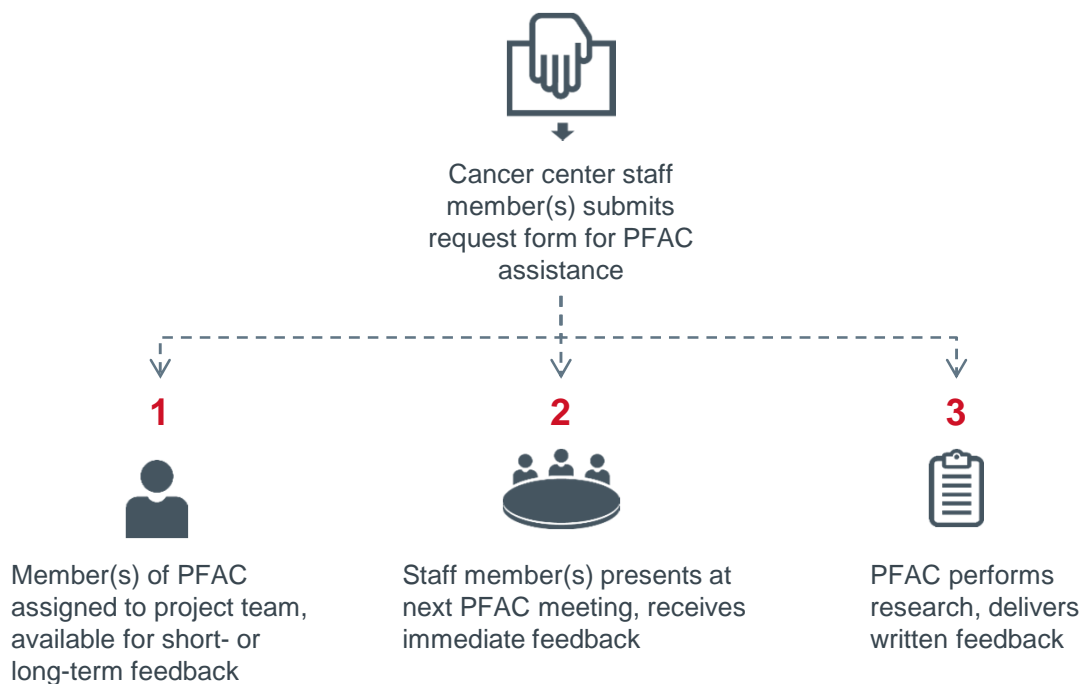
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VI. Wrap-up

- A. Required documents (which they are instructed to bring to the next meeting):
 - HIPAA & IT Security Forms, Consent to Photograph
 - If applicable: Honoraria for family faculty; stipends for regular hospital committee attendance; recording time; W9 submission
- B. Summarize to-dos and key milestones to achieve before the next meeting and email them out to the group after the meeting

Step 8: Ensure Staff Access to PFAC Feedback

Providing cancer center staff with a formalized feedback process promotes PFAC visibility and ensures staff access to PFAC feedback. Fox Chase Cancer Center utilizes a formalized feedback request form that cancer center staff or project teams submit to the PFAC chair. Upon submission, the PFAC chair either assigns PFAC member(s) to the project team based on member availability, adds the requesting parties to the next PFAC agenda so the council can provide immediate feedback, or tasks the PFAC with performing outside research upon which they will provide feedback.



Examples:

PFAC members assigned to Lean teams

PFAC members offer immediate feedback on plans for cancer center special event

PFAC members individually navigate new patient education website, provide written feedback

In addition to a formalized feedback process, the council should have a standardized request triage method managed by a designated contact on the PFAC, often the chair. A sample feedback request form is provided on the next page.

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Sample Feedback Request Form



PROJECT REQUEST FOR THE PFAC

Please complete this form and email it to First.Last@email.com

Person Submitting: _____ Date Submitted: _____

Office Telephone: _____ Ext: _____ Fax: _____

Email: _____ Clinic/Department: _____

Unit: _____

Project Title with Brief description: _____

Background

Project Objectives

Supporting Materials Attached? (Data, Brochure, Policy, etc.):

Yes _____

No _____

Estimated Duration of Project: _____

Target Completion Date: _____

Thank you for contacting the Patient and Family Advisory Council for assisting with your projects!

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Step 9: Maintain PFAC Engagement

It is important to continually develop new and innovate ways to maintain an active and fully-leveraged PFAC. Several tactics to ensure continued PFAC engagement:

- Work with the cancer center's website administrator to create a dedicated PFAC page that includes PFAC information such as mission, council members, past projects etc. Some PFAC web pages
- Every six months, perform either formal or informal evaluation of member satisfaction with the council and allow members to illuminate council strengths and potential areas of improvement
- Hold special annual meetings to recognize noteworthy projects or accomplishments

Source: Oncology Roundtable interviews and analysis.