

# Patient and Family Advisory Council Handbook



A special thanks to the PFAC Steering Committee for their leadership and guidance on creating this handbook:

Marion Martin of Roper St. Francis

Caroline Delongchamps of MUSC Health

Sharyn Barlik of Bon Secours St. Francis

# Patient Family Advisory Councils

Patient and Family Advisory Councils (PFACs) are a productive way for patients and families to partner with a healthcare system to provide guidance on how to improve the patient and family experience. Healthcare organizations have embraced councils to not only learn from the consumer's point of view and experience but also to integrate their ideas into service delivery and quality improvement efforts. This unique perspective from patients and families can positively impact care and assist with engineering a more customer-centered approach to the work of healthcare organizations. The purpose of this handbook is to provide tools that will assist with developing a PFAC.

## Patient and Family Centered Care

According to the Institute for Patient and Family Centered Care, patient-family centered care calls for new approaches to healthcare that are grounded in partnerships between providers, patients and families. Collaboration between these partners is necessary for the delivery of safe and effective care, and as such these relationships should be central to new processes.

The Institute Outlines Four Core Concepts for Patient and Family-Centered Care\*:

- 1. Dignity and Respect:** Healthcare 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 healthcare leaders collaborate in policy and program development, implementation and evaluation, facility design, and in professional education, as well as in the delivery of care.

\*From Advancing the Practice of Patient- and Family-Centered Care in Hospitals, available at [ipfcc.org/pdf/getting\\_started.pdf](http://ipfcc.org/pdf/getting_started.pdf)

## Mission, Vision, and Goals

A mission and vision statement should be determined to guide the work of the council. It is imperative that the mission and vision are aligned with that of the organization. This ensures the work of the council is meaningful and goal-directed. Identifying the scope of influence will be important to establish a clear understanding of the council's role (see **Attachment #1, Goals of Patient and Family Advisory Councils**, and **Attachment #2, Examples of Projects to Consider**).

## Creating an Infrastructure

Generating support from executive leadership is the first step to developing and sustaining a successful PFAC. Demonstrating a passion for patient and family centered care is of utmost importance for this leader. Once selected, a staff liaison or leader should be appointed or hired to formulate an advisory council. The reporting structure and job description can be established at this time to create a framework for moving forward with PFAC development.

Identifying and involving stakeholders that will be involved with the efforts from the start assures buy-in, builds a foundation for successful implementation, and solidifies the value in creating an advisory council. A steering committee and planning team can be helpful with mapping and operationalizing the council as well. Creating bylaws will outline the structure and foundation for operationalizing the council. It can be very time consuming to create bylaws but there are many hospitals that have already

blazed this trail. It can be helpful to use the work of others as a guide when creating bylaws (see **Attachment #3, MUSC Health and Roper St. Francis bylaws**).

## Membership and Recruitment of Advisory Council

PFACs are comprised of former patients and family members whose experiences make them good candidates for serving in an advisory role and supporting staff. Sources for potential members can be staff recommendation, physician suggestions, word of mouth, tracked grievances or complaints. It is recommended that the CEO of the organization extend a formal invitation to the candidate for possible membership (see **Attachment #4 Recommended Member List, Attachment #5 Recruitment Resource List** and **Attachment #6 Letter of Invitation**).

Once the candidate expresses interest in serving on the council, a formal interview can be set up. The goal of the interview will be to determine which applicants possess the qualities that will ensure success of the council. Learning more about their conflict resolution skills, experiences in healthcare, interests and other abilities will assist in determining if they are an appropriate fit for the council. Selecting individuals that can see beyond personal experiences to improve healthcare experiences for others makes for the ideal council member. In order to be effective as a council, the group should be diverse and represent the community in which they serve (see **Attachment #7 Selection Criteria and Patient and Family Advisory Council Interview Form**).

## Operationalizing the Council

Viewing the council as an integral part in achieving the organization's mission will enhance the work of the council. Nominating a chairman and co-chairman to lead council meetings formalizes a structure and encourages progress from the onset. The organization would benefit from providing secretarial support for mailing, reserving rooms, sending out planners, and other logistics. Establishing working sub-committees and including council members on organizational committees develops true partnerships and influences decisions to become more patient and family centered. Creating a timeline for implementation of a PFAC to keep stakeholders informed and maintain momentum is also highly recommended (see **Attachment #9 Timeline for Implementation**).

Orientation of council members should include the following:

- Orientation packet
- Introductions
- Personal stories (shared by council members) that inspired them to join council
- Mission and Vision Statements
- Review goals and role of council
- Outline role and responsibilities of member, officers, staff, physicians, and administration on council
- Meeting logistics (frequency, time, location, parking, meals/refreshments, etc.)
- Nametags and security
- Confidentiality and HIPAA
- Evaluation for each meeting

## Tracking and Annual Reporting

Capturing the work of the council by retaining agendas, documenting activities, and keeping minutes will be key to tracking progress. An annual report should be prepared and presented to the executive team and board to demonstrate the work and share accomplishments of the PFAC (see **Attachment #10 Sample Orientation Agenda** and **Attachment #11 Minutes Template** for a sample).

## Health Insurance and Portability Act (HIPAA)

Addressing concerns with leadership and staff around HIPAA compliance will be necessary to ensure PFAC's can function as partners in the organization. Education is the key to informing and supporting advisors and staff on protecting the individual privacy of patients. The following recommendations outline important points to consider regarding HIPAA education for advisors:

1. Include HIPAA training in orientation and ongoing meetings. This will ensure understanding of the advisor's role in protecting patient privacy.
2. Encourage the advisory council to always be mindful of their role in advocating for each patient and identified family members to receive information that will improve safety and care during and after hospital stay.
3. Conduct background checks on advisors serving on the organization's boards, internal committees, task forces and council.
4. Require that all advisors signed a confidentiality statement prior to orientation.
5. Provided ongoing education to council members on HIPAA rules and regulations.
6. Use de-identified data in council meetings to protect the privacy of individuals.

(See **Attachment #12 Fact Sheet on HIPAA Compliance**)

## Staff Education

Gaining the support of front line staff requires educating and involving them in the process for PFAC development. It is recommended that all staff be required to attend training on the purpose of PFACs, role of advisors, and suggestions on how the staff can include advisors to improve care.

## Infection Control

If advisors are visiting units and coming in contact with patients, it is recommended that they visit employee health for preventive screenings and vaccinations. Council members should also be advised on proper handwashing technique when visiting clinical areas.

This handbook was created by SCHA and the PFAC Steering Committee using the following sources:

Agency for Healthcare Research and Quality (AHRQ) [www.ahrq.gov](http://www.ahrq.gov)

Institute for Healthcare Improvement (IHI) [www.ihl.org](http://www.ihl.org)

Institute for Patient- and Family-Centered Care (IPFCC) [www.ipfcc.org](http://www.ipfcc.org)

# *attachments*

## Table of Contents:

- 1** Goals of Patient and Family Advisory Councils (5)
- 2** Examples of Projects to Consider (6)
- 3** Samples of MUSC and Roper St. Francis Bylaws (7)
- 4** Recommended Member List (14)
- 5** Recruitment Resource List (15)
- 6** Letter of Invitation (16)
- 7** Selection Criteria (17)
- 8** Patient Family Advisory Council Interview Form (18)
- 9** Timeline for Implementation (19)
- 10** Sample Orientation Agenda (20)
- 11** Minute Template (21)
- 12** Fact Sheet on HIPAA Compliance (22)
- 13** Recommended Toolkit and Additional Resources (25)

# *attachment 1*

## **Goals of the Patient & Family Advisory Councils**

- To promote patient-and family-centered care principles
- To identify and establish priorities related to policy, programs and practices that support patients and families
- To assist in developing strategies to strengthen communication and improve collaboration between healthcare providers and patients and families
- To promote patient and family access to information
- To make recommendations in designing educational resources useful to patients and families for making healthcare decisions
- To contribute to the education of current and future health care providers in the principles of patient- and family-centered care
- To offer input in planning new facilities and facility renovations
- To improve patient and family satisfaction
- To serve as a link between the community and the hospital
- To integrate into the organization by serving on key committees
- To share information from the patient-family perspective on care and service
- To collaborate with hospital leaders and staff on issues that may impact the safety of patients-families

# *attachment 2*

## **Examples of Projects to Consider**

- Publicly reported measures (CAHOS survey)
- Facility upgrades
- Communication of wait time/delays in ED or other waiting rooms
- Visitor policy
- Noise reduction
- Education or other information/materials for patients
- Signage
- New menus
- Communication tools
- Designing new areas
- Signage
- Other ideas to make the patient-family experience better



# *attachment 3*



## **MUSC Health** **Patient and Family Advisory Council Bylaws**

### *introduction*

#### **Our Purpose**

The MUSC Health Patient and Family Advisory Councils (PFAC's) are a partnership between patients, caregivers, and MUSC Health dedicated to advancing comprehensive and compassionate patient- and family-centered health care to the communities we serve. We do this by working in active partnership with our health care providers to:

- Strengthen communication and collaboration among patients/families, caregivers and staff in a respectful and trusting environment
- Promote patient and family advocacy and involvement
- Recommend and participate in MUSC Health programs, services, and policies

#### **Our Vision**

The vision of the MUSC Health Patient and Family Advisory Councils is to achieve a level of care where patient and family involvement is welcomed and optimized. The goal of the partnership between the Councils and MUSC Health is to implement solutions for delivering care that is safe, equitable, effective, efficient, timely and patient and family centered.

#### **PFAC Organization**

##### **1. Members**

###### **A. Eligibility**

Patients, family members and staff from the MUSC Health System are eligible to become members of the Council. Members should be committed to building a partnership to understand the needs of the constituents they represent and to implement programs and policies to address health care challenges within USC Health, regardless of location. Each council member must submit an application and be interviewed. The Council shall strive to create a membership that reflects the diversity of the MUSC patient population in terms of medical diagnoses, geographic areas and cultural diversity.

## **B. Duties**

Council members are expected to attend and actively participate in regularly scheduled meetings as well as various committees or projects that will require additional hours. Council members should inform the Chair or Council Liaison of expected absences from meetings. A council member should not miss more than three regular meetings a year, unless such member has advised the Chair or Council Liaison of an expected absence to maintain active membership status.

## **C. Membership Term**

An initial term of Active Membership consists of two years, renewable yearly for up to six years. Standing members, i.e. Liaison, Administration, Directors, etc. have no term limit. Active members will be polled for their preference for continued membership at the end of each year by the Council Liaison.

## **D. Size**

Smaller groups encourage greater discussion and participation by all members. However, larger groups will provide a wider range of experiences and input. There is no minimum or maximum limit to the size of the Council and is left up to the discretion each Council.

## **E. Vacancies/Leaves of Absence**

Council members may resign or request a leave of absence from the Council at any time during their term. This request may occur when unusual or unavoidable circumstances require that the member be absent from meetings and activities for 3 to 6 months. The member should submit his/her leave of absence request in writing to the Chair/Co-Chairs or Council Liaison, stating the reason for the request and the length of time requested. If a member cannot return at the end of the requested leave of absence, the Council Chair and Liaison will review the individual's membership preference and ability to remain active. If the member is not capable of remaining an active member, he/she shall resign from the Council. At the time of a member's resignation, the Council may choose to add a replacement at that time or to leave the position open until the next rotation of members.

## **F. Recruitment**

Council members and MUSC Health staff will be utilized to recruit and recommend future members.

## **G. Selection**

Potential members must fill out a Patient Family Advisory application. The Council Liaison will conduct an interview. After successful completion of the interview the candidate will be invited to a Council meeting. The Chair, with consideration of comments from the Council, will determine the candidate's eligibility for membership. The Council Liaison will notify the potential member of the decision.

Membership on a Council requires successful completion of the registration process as a volunteer, including but not limited to: interview, a health screening which includes TB screening and flu vaccine, a criminal background check and an orientation. Agreement of MUSC Health confidentiality and compliance guidelines is mandatory.

## **H. Inclusion**

The goal for Patient Family Centered- Care at MUSC Health is for the Council membership to best represent the MUSC Health patient population.

## **I. Associate Members**

Those who wish to participate in the Council, but are not current/former patients and/or family members from MUSC Health System, may apply to become Associate Members. The Chair/Co-Chair, with consideration of comments from the Council, will determine the candidate's eligibility for membership. They will not have Council voting privileges, but they may participate on Council committees and projects where it is deemed appropriate.

## 2. Roles and Duties

### A. Council Chairman/Co-Chairmen

The Chairman/Co-Chairmen will be responsible for setting Council meeting agendas, chairing and conducting meetings, coordinating between Council members and staff, and providing leadership for the Council members, along with assistance from the Council Liaison. The Chair/Co-Chairs will also serve on MUSC Health committees where specifically requested.

### B. Nomination Procedure

Candidates for the Chairman or Co-Chair positions shall be nominated from any active Council member. Candidates for the Chair position, having at least one year of experience, will be nominated from the council members. Nominations will be accepted from the floor at the June meeting, prior to the official election at the July meeting.

### C. Election Procedure

Officers will be elected by the affirmative vote of two-thirds of the quorum present at the next meeting.

### D. Term

The standard term of the Chair/Co-Chair is two years with the option of re-election for another term.

### E. Council Liaison

The Council Liaison will be responsible for the logistics of the Council meetings. Examples include reserving meeting space, parking and meals. The Liaison will also assist the Chair/Co-Chair with setting Council meeting agendas, conducting meetings, coordinating between Council members and staff, and providing leadership for the Council members. The Liaison will handle the application process, to include the initial phone interview, background check, employee health clearance and orientation process. The Liaison will also assist with recruitment of new Council members.

### F. Guest

Guests should have prior consent by the Chair and Council Liaison and are welcomed on an 'as needed' basis.

### G. Leader Sponsor

A Leader Sponsor is defined as a MUSC Health employee who holds a leadership position (physician, administration, etc.), specifically related to the Council patient population, who supports the Council as the Champion and provides guidance and resources as needed for the Council to be successful.

## 3. Meetings

### A. Regular Meetings

Regular meetings, not to exceed 12 meetings per year, of the MUSC PFAC will be held on a regular schedule set by the Chair and Council Liaison annually unless otherwise requested by the Council.

### B. Special Meetings

Special meetings, not to exceed 6 additional meetings per year, can be called by the Chair or Co-Chair as necessary. Council members will be given at least 48 hours' notice of the meeting schedule and agenda. Those not able to attend the meeting may participate via conference call (set up by Liaison). Special meeting shall be exempt from the attendance requirement set forth in 1B.

### **C. Voting & Quorum**

Any voting will require the presence of a minimum of two-thirds (2/3) of the quorum. A quorum is defined as two-third (2/3) of the voting members present. All motions must have a majority of two-thirds to pass.

### **D. Meeting Minutes**

Minutes should be kept and distributed widely by Council Liaison so the activities of the Council are made aware to as much of the organization as possible.

## *committees*

The MUSC Health System has multiple committees, IMPROVE groups and teams on which members may serve to improve the overall patient experience. Additionally, from time to time, it may be necessary to create a special committee or task force in order to further the work of the Council. The initiation of such a committee may be requested by any Council member.

## *amendment procedure*

These Bylaws may be amended at any regular meeting of the Council by the affirmative vote of two-thirds of the quorum present and voting, provided that the amendment has been submitted in writing at the previous regular meeting.

## *confidentiality*

The MUSC Health System is committed to treating our patients with respect for their personal dignity and right to privacy, and to protect the confidentiality of all information concerning their care. MUSC Health and all Council members will maintain patient confidentiality in accordance with the requirements of state and federal law. Further information can be found in Hospital Policy C-003 Patient Confidentiality.



## **Roper St. Francis**

### **Bylaws and Rules for Patient and Family Experience Council (PFEC)**

## *purpose*

The Patient and Family Experience Council (PFEC) will empower patients and families to take an active role in improving the

patient experience at Roper St. Francis Healthcare. The PFEC promotes patient and family-centered care and serves as an experience resource for employees, staff, and administration.

## *structure*

The PFEC will consist of ten (10) to twelve (12) members representing the diversity of our RSFH patient community. Several staff members may also serve on the PFEC. The structure of the council may change over time, and patients themselves may lead the council if appropriate.

Members are selected based on the variety of backgrounds, experiences, and strengths that they bring to the group. A council that accurately represents the broad spectrum of families served by RSFH will be the ongoing goal.

## *roles and responsibilities*

### **Patient/Family Members:**

- Attend each PFEC meeting or notify a staff member in advance if unable to meet.
- Engage thoughtfully and constructively around the issues and ideas discussed during each session.
- Be respectful of the unique background and perspective of each individual member.
- Rather than focusing on what is not working, individuals should be proactive in driving improvement and bring creative ideas for change.

### **Staff/Employee Members:**

- Attend each PFEC meeting.
- Prepare meeting agendas.
- Identify, invite, vet, and orient potential PFEC patient and family members.
- Be prepared to facilitate discussions and engage all members.
- Provide a report back to the PFEC of progress on ongoing projects and any hospital changes of interest to the group.
- Assist with PFEC operations behind the scenes (i.e. book rooms, order food to mention two).
- Help the PFEC achieve established goals by removing or minimizing potential barriers (work with RSFH patient representative as appropriate).

### **Outputs of the PFEC:**

- The PFEC shall issue an Annual Report outlining its activities and achievements throughout the year, evaluating the operation of the PFEC and providing recommendations for the future.
- The PFEC will provide regular updates to the Vice President of Mission.
- The PFEC shall engage in a variety of information gathering activities such as open discussion with patients and family members, including focus groups, surveys, and open forums.
- The PFEC may engage in educational and policy-making forums.
- The PFEC may serve as community liaisons, engaging other patients and families in various programs as necessary.
- Members of the PFEC may also serve on other committees, as appropriate, across the hospital system.

## **Orientation, Training, and Badges**

All selected patient and family applicants will complete an application process as well as an orientation. Approved applicants will receive badges and should wear their badges whenever they are on-site participating in a PFEC session. Badges do not offer additional security access to the hospital and should not be worn during clinic visits or inpatient stays. Staff advisors and standing members should wear their hospital badges during sessions as well.

## **Confidentiality**

PFEC members must not discuss any personal or confidential information revealed during a council meeting outside of these sessions. Council members must adhere to all applicable HIPAA (Health Insurance Portability and Accountability Act of 1996) standards and guidelines. Examples include, but are not limited to:

- Staff members must not mention patients or families by name or provide information that could identify a specific patient or family.
- Patient/Family members must not mention other patients or families by name or provide identifying information.
- Patient/Family members should avoid mentioning specific staff members by name.

If an advisor violates these guidelines, a staff member will remind them of the guidelines. If a member continues to break the HIPAA guidelines, they must repeat the HIPAA orientation session. If they continue to fail to comply, their membership status will be re-evaluated.

## **PFEC Service**

The initial members of the PFEC will serve for staggered terms of up to two years. Five to six members will serve for one year: five to six members will serve for two years. Thereafter, members will serve for equal terms of one year being appointed and retiring in rotation.

Initially the community and RSFH employees will be invited to submit nominations for the eight (8) to twelve (12) PFEC community members. Potential council members will complete and submit a written application to be reviewed by the PFEC Selection Committee. Chosen applicants will be interviewed and chosen by members of the selection committee. The selection committee will appoint up to five (5) Roper St. Francis Healthcare employee representatives to the PFEC.

## **PFEC Meetings**

Meetings will be held every other month, on a day and time that best meets the schedules of all members.

Each meeting will be two (2) hours in length, with a meal served before the meeting's start time. If possible, it is encouraged to post the meeting schedule in a place accessible to all members.

## **Agenda**

Meeting agendas will be set by the designated staff/employee member and distributed to the membership prior to each session.

## **Meeting Minutes**

The designated staff/employee member will distribute the minutes in a timely manner to all PFEC staff and patient members.

## **Attendance**

It is expected that the members of the council will make every attempt to attend every session during their term. Participation by every patient will provide the most effective meeting and make the most impact on the patient experience at RSFH. However, in extreme cases, members may not be able to make one or more sessions. If this is the case, notification to a staff/employee member as soon as possible is expected in order to make any needed adjustments prior to the group meeting.

### **Inclement Weather**

Business meetings will be canceled if Charleston, Berkeley, or Dorchester counties declare an emergency due to hurricane warnings. If a member resides in a different county that experiences weather that does not allow the member to attend a session, that member must notify a staff/employee member to have their absence excused. Should a business meeting be canceled due to inclement weather, all council members will be notified in a timely manner.

### **Termination**

The Mission office and/or the PFEC reserve the right to dismiss any PFEC member who is not compliant with the above rules and bylaws.

Drafted by: Sr. Kathy Adamski, Director of Mission  
01/16/13

# attachment 4

## Recommended Council Make Up

- Vice-President, Quality or other executive team lead
- Director, Manager, or Coordinator of Patient Relations or Patient Experience
- Director of Risk Management, Patient Safety Officer, or Compliance Officer
- 1 Nurse Manager
- 1 Administrative Support Person
- Ratio of no more than 1 staff member for every 4 council members
- Current or past patients and/or family members

Make a list of your council members:

Name	Position



# *attachment 5*

## **Sample Recruitment Resource List**

As your council develops, making a list of potential PFAC council members will assist with developing a pool for members. This will be particularly helpful as physicians, nurses, and others make recommendations on members. Creating a document that can be kept in one place will keep the information current. An example of data that would be helpful is as follows:

Date of Referral	Name of Potential Candidate	Role	Contact Information	Referral Source

# attachment 6

## Sample Patient Family Advisory Council Letter of Invitation

Name  
Address  
City, State, Zip

Dear (patient/family member name):

(Name of Organization) is committed to partnering with patients and families to assist us with creating a patient centered approach to the care we deliver every day. We recognize that in order to best serve the patients and families in our community, it is important for us to include patients and families in decision making.

Our Patient Family Advisory Council offers a unique opportunity for us to partner with our patients and families to better meet the needs of our patients. We are reaching out to individuals in the community who are interested in joining our advisory council to provide us with constructive advice and feedback to improve the experiences of our patients.

The criteria for serving on the council is as follows:

- Experience as a patient or family member in the past year
- Time to attend regular meetings
- Ability to make decisions as a group and support the decisions of the council

We invite you to consider completing the enclosed application and returning it in the enclosed self-addressed stamped envelope. Once your application has been received, we will contact you to join us for an interview with one of our hospital staff.

Thank you for your interest in assisting us with improving the care we provide to our patients.

Sincerely,

---

(Insert CEO name and credentials here)

Chief Executive Officer

# *attachment 7*

## **Selection Criteria for Council**

### **Qualities and Skills of Patient and Family Advisors**

Seek individuals and families who are able to:

- Share insights and information about their experiences in ways that others with can learn from them.
- See beyond their own personal experiences.
- Show concern for more than one issue or agenda.
- Listen well.
- Respect the perspectives of others.
- Speak comfortably in a group with candor.
- Interact well with many different kinds of people.
- Work in partnership with others.

#### **Other recommendations:**

Seek patients and families who represent a variety of clinical experiences such as type of illness, families, and programs utilized.

Include patients and families who have both positive as well as negative perceptions of experiences.

Seek patients and families who reflect the diversity of those served by the hospital or clinic—racial, cultural, religious, socioeconomic, age, educational background, and a variety of family structures.

#### **Resource:**

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE  
6917 Arlington Road, Suite 309 • Bethesda, MD 20814  
Phone: 301-652-0281 • Fax: 301-652-0186 • [www.ipfcc.org](http://www.ipfcc.org)

# *attachment 8*

## **Sample Patient and Family and Advisory Council Interview Form**

Date: \_\_\_\_\_

Interviewer: \_\_\_\_\_ Candidate: \_\_\_\_\_

1. Talk about some of your most memorable experiences in healthcare. This can be an experience as a patient or as a family member.

---

---

---

2. What special interest or skills would you like to offer to the council?

---

---

---

3. Tell me about a time you had a disagreement with someone and how you handled it. This could be related to a co-worker, friend, family member, or others.

---

---

---

4. If you serve on the patient family advisory council, what ideas do you have to bring to the council to improve the patient or family experience based on your experiences in healthcare and the community?

---

---

---

5. Discuss the plan for frequency and times the council will meet. What is your availability for meeting times?

---

---

---

# attachment 9

## Sample Timeline for Intervention

Task	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6
Gain Administrative Approval						
Appoint Liaison						
Hold Planning Meetings						
Recruit PFAC Members						
Set Up Orientation						
Hold First Meeting						

# *attachment 10*

## **Sample Meeting Agenda**

### *patient and family experience council*

#### **Orientation Agenda**

Date/Time:

Name of Organization/Unit:

1:00-1:10 p.m. .... **Welcome**

1:10-1:15 p.m. .... **Introductory to PFAC**

1:15-2:30 p.m. .... **Overview of (name of organization)**

- a. What is a PFAC?
- b. Why do we need a PFAC?
- c. What is your role as a PFAC member?

2:30-2:45 p.m. .... **Break**

2:45-3:15 p.m. .... **HIPAA (Privacy Issues/Confidentiality)**

3:15-4 p.m. .... **Infection Control**

**Nametags/Security**

**Parking**

**Effective presentation of issues/Collaboration with hospital staff (clinical and non-clinical)**

4-4:30 p.m. .... **Bylaws and Structure**

# attachment 11

## Minutes Template

(sample)

MEETING CALLED BY \_\_\_\_\_

TYPE OF MEETING \_\_\_\_\_

FACILITATOR \_\_\_\_\_

NOTE TAKER \_\_\_\_\_

TIMEKEEPER \_\_\_\_\_

ATTENDEES \_\_\_\_\_

### AGENDA TOPIC:

DISCUSSION

---

---

---

CONCLUSIONS

---

---

---

ACTION ITEMS

PERSON RESPONSIBLE

DEADLINE

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
_____	_____	_____
_____	_____	_____
_____	_____	_____

### UPCOMING MEETINGS:

Date	Time	Location
_____	_____	_____
_____	_____	_____
_____	_____	_____

# attachment 12

## Fact Sheet on HIPAA Compliance

Many hospitals and practices have questions about how to abide by HIPAA privacy and security rules while also working to advance patient- and family-centered care and partner with patients and families. In addition, many hospitals want to ensure that they adhere to Joint Commission standards.

Concerns about violating HIPAA privacy and security rules and Joint Commission standards – or an incomplete understanding of the rules and/or standards – often prevent the sharing of important information with patients and families.

**It is important to note that HIPAA gives patients the right to see and receive a copy of their health information; there is no wording within the HIPAA privacy and security rules or the Joint Commission standards that prohibits health care providers from sharing information with patients and designated family members or partnering with patients and families either at the point-of-care or in governance.** Furthermore, it should be noted that the Joint Commission is supportive of both patient and family engagement and of partnering with patients and families in health care redesign and improvement (e.g., patient and family advisory councils) to achieve quality and safety goals.

This document highlights frequently cited concerns and offers ways to address them.

## *point-of-care examples*

### **Rounds and Nursing Change of Shift Reports at the Bedside**

Rounding and change of shift reports at the bedside enable patients and their designated family members to participate in discussions about the patient's health and treatment. When encouraged to actively participate, patients and family members share critical information with health care providers in these discussions.

*Concern: In rooms with multiple beds, does rounding or change of shift at the bedside (in earshot of other patients) violate HIPAA rules or Joint Commission standards? How do we ensure patient privacy when interacting with family members?*

- HIPAA allows for normal hospital and physician operations. Clinicians are freely allowed to discuss patient care for treatment purposes, and conversations may take place with patients and designated family members, unless the patient objects. Consider that, in multi-bed rooms, patient health information is commonly/frequently shared in ways that could be overheard by others in the course of providing care (for example, a nurse may comment to a patient on her blood pressure, or a physician may discuss discharge plans with a patient).
- HIPAA is intended to support greater patient control over their health information, and the sharing of patient information to improve care and safety. Participation in rounds or change of shift reports allows patients and family members to take greater control over their health and health information by: (1) learning about the patient's condition, medications, treatments, symptoms, and problems to look out for, and (2) providing additional helpful information to providers.
- There is nothing in the Joint Commission standards that prohibit rounding or nurse change of shift report at the bedside. In fact, the Joint Commission has expressed explicit support for family involvement.



## Additional Suggestions:

- Design bedside change of shift reporting and rounding protocols to be sensitive to patient privacy needs. Involving patient and family advisors in designing or adapting these processes will help to ensure that patients and families are appropriately involved in their care and comfortable that their privacy is respected. Some potential strategies to consider include:
- At the beginning of a hospital stay, describe to patients and designated family members the process for rounding and change of shift report at the bedside. Be sure they understand that conversations may be overheard in shared rooms. Ask patients and families if they would like to participate in rounds and change of shift reporting at the bedside.
- Ask patients to identify designated family members and whether there are issues they would prefer to remain private if rounds or nursing shift reports are conducted with family members present.
- Ask the patient (and for a child or an incapacitated adult, the authorized parent, guardian, or designated proxy) to identify any family members who should not participate in rounds or other discussions with staff.
- Consider environmental changes to help safeguard privacy while promoting more patient- and family-centered care – for example, soundproof dividers or curtains for semi-private rooms.

## Encouraging Family Presence

Family members are not “visitors” – they provide critical support for patients during and after a hospital stay, and are an important resource for patients’ care teams. In recognition of the important role of families, many hospitals are moving away from traditional “visiting hours” and adopting policies that encourage family presence and participation.

*Concern: If my hospital encourages “family presence” in lieu of “visiting hours”, won’t it be more difficult for providers to talk about sensitive medical information with patients? How can hospitals support family presence while protecting patient privacy?*

- Ask patients to identify the family members they would and would not like to participate in their care, and how they would like to involve them. This will ensure sensitive patient health information is shared according to their wishes.
- In the case of shared rooms, provide guidance to patients and their families that will help them be respectful of other patients and families who share the same patient room (i.e. keep information they might hear confidential).
- Engage patient and family advisors in developing guidelines for family presence that involve family members according to the patient’s wishes. This work could include drafting sample language that personnel could use to deal with difficult situations, such as family members who demand access to personal health information against patient wishes.

## *governance examples*

### **Patient and Family Advisor Participation in Governance**

Involving patients and families in quality improvement workgroups, patient safety task forces, and bodies such as patient and family advisory councils (PFACs) is a key strategy for delivering patient-and family-centered care and ensuring that the end-results meet the needs of patients and their families. In some case, these bodies review data on readmission rates, medical errors, or quality and safety information.

*Concern: How can hospitals and practices make sure they are adhering to HIPAA privacy and security rules and/or Joint Commission standards while including patient and family advisors in these important discussions?*

- Conduct HIPAA trainings for patient and family advisors to ensure they understand the HIPAA privacy and security rules and their role in ensuring adherence to HIPAA rules.
- Conduct background checks on advisors who will be involved in regular ongoing task forces, committees, councils, and boards.
- Create guidelines on information-sharing and confidentiality that all advisors are asked to follow and require that all advisors sign a confidentiality statement. Sample wording: “As a non-employed committee member, you may have access to protected health information. It is important that you recognize that any protected health information can only be used and disclosed as permitted by law. This information cannot be shared by written, verbal, or e-mail communication at school or home; with friends or family; or outside the hospital, clinic, or other health care facility unless specifically permitted by law.”
- De-identify sensitive data prior to consideration by any governance bodies to comply with HIPAA’s “minimum necessary” standard.

## *important steps for success*

1. Communicate clearly with clinicians, staff, patients and families that information sharing is a priority and key to delivering high quality, safe care.
2. Implement policies and processes that encourage information sharing.
3. Provide all employees with training and guidance about how to share information in ways that adhere to HIPAA privacy and security rules and Joint Commission standards. Because of current misconceptions, it will be important to emphasize to all employees that there is no wording within the HIPAA privacy and security rules or the Joint Commission standards that prohibits health care providers from sharing information with patients and designated family members or partnering with patients and families either at the point-of-care or in governance. Engage the Risk Management Department and ask personnel to clarify any misconceptions about the HIPAA privacy and security rules.

### Resources for fact sheet on HIPAA Compliance:

Guide to Patient and Family Engagement in Hospital Quality and Safety. AHRQ (June 2013)  
Available at: <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/index.html>

HIPAA – Providing New Opportunities for Collaboration. Institute for Patient- and Family-Centered Care (2004).  
Available at: <http://www.ipfcc.org/advance/hipaa.pdf>

Essential Allies – Patient, Resident, and Family Advisors: A Guide for Staff Liaisons. Institute for Patient and Family-Centered Care (2013).  
Available at: [http://resources.ipfcc.org/product\\_p/32063-1.htm](http://resources.ipfcc.org/product_p/32063-1.htm)

Changing Hospital “Visiting” Policies and Practices: Supporting Family Presence and Participation. Institute for Patient- and Family-Centered Care (August 2010).  
Available at: <http://www.ipfcc.org/visiting.pdf>

# *attachment 13*

## **Recommended Toolkit**

<http://www.ipfcc.org/tools/Patient-Safety-Toolkit-04.pdf>

## **Recommended Resources**

**Agency for Healthcare Research and Quality (AHRQ)**

[www.ahrq.gov](http://www.ahrq.gov)

**Consumers Advancing Patient Safety (CAPS)**

[www.patientsafety.org](http://www.patientsafety.org)

**Institute for Healthcare Improvement (IHI)**

[www.ihl.org](http://www.ihl.org)

**Institute of Medicine (IOM) International Alliance of Patients' Organizations (IAPO)**

[www.patientsorganizations.org](http://www.patientsorganizations.org)

**Institute for Patient- and Family-Centered Care (IPFCC)**

[www.ipfcc.org](http://www.ipfcc.org)

**National Patient Safety Foundation (NPSF)**

[www.npsf.org](http://www.npsf.org)

**World Alliance for Patient Safety: Patients for Patient Safety**

[www.who.int/patientsafety/patients\\_for\\_patient/en](http://www.who.int/patientsafety/patients_for_patient/en)