



CREATING PATIENT AND FAMILY ADVISORY COUNCILS

▼ Purpose/responsibility of the advisory council

- Serves as advisory resource to administration and staff of the organization or one of its programs
- Promotes improved relationships between patients, families, and staff
- Provides a vehicle for communication between patients, families, and staff
- Provides a venue for patients and families to provide input into policy and program development
- Provides an opportunity for patients and families to review recommendations referred to the council by staff or administration and provide input
- Provides an opportunity for patients and families to actively participate in improving quality, safety, equity, and the experience of care
- Channels information, needs, and concerns to staff and administration
- Actively helps implement changes
- Provides input into educational programs for staff
- Collaborates as partners with staff, physicians, and administration in the planning and operation of specific programs
- Provides opportunities for staff to learn from the perspectives of patients and families
- Provides a safe venue for patients and families to provide input in a setting where they are receiving care

▼ Benefits of an advisory council

- Provides an effective mechanism for receiving and responding to feedback
- Results in more efficient planning to ensure that services address the needs and priorities of patients and families
- Leads to increased understanding and partnership between patients and families and clinicians and staff
- Promotes respectful, effective partnerships between patients and families and health care professionals
- Offers a forum for developing creative, cost-effective solutions to problems and challenges faced by the program or organization

- Assists the organization in achieving its safety, quality, equity, and experience of care outcomes
- Provides a link between the organization, its surrounding community, and community groups

Note: The council should not be seen as a place where an individual council member brings their personal grievances about clinic/hospital experiences to be dealt with and solved. Personal experiences should be used as examples when discussing a program or service. Council members should also bring experiences and perceptions of other patients and families to the discussion. The council should not be seen as a support group. Patients or families who are grieving over a loss should be directed to a support group.

▼ **Representing the patients and families served**

Seek patients and families who represent a variety of clinical experiences such as type of condition, illness, and programs utilized. Seek a broad range of experiences. Include patients and families who have both positive as well as negative perspectives of experiences.

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

▼ **Qualities and skills of patient and family advisors**

Identify patients, families, staff, and community organizations that can recommend potential members. Patient experience personnel, physicians, nurses, managers, social workers, child life personnel, and volunteer coordinators as well as other professionals can recommend candidates.

Seek individuals and families who are able to:

- Share insights and information about their experiences in ways that others 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

▼ **Recruitment**

- Ask staff for suggestions
- Post and advertise within the units or clinics
- Put notices in websites, social media platforms, and publications
- Send direct mail to present and former patients

▼ Developing the council

Consider developing a patient and family workgroup as a precursor to a more formal council. A workgroup is a quick way to get patient and family participation in activities. The informal structure of a workgroup may be less threatening to staff. Someone internal or external to the organization can facilitate the workgroup. The latter provides an opportunity for staff, patients, and families to become comfortable over time with new ways of working together. A workgroup is a place where staff, patients, and families can learn and practice new collaborative skills and a place to gain confidence in the collaborative process. It provides an opportunity for natural leaders to emerge. A workgroup can provide invaluable information to staff until a permanent council and/or a variety of other collaborative endeavors are established.

▼ Council structure

Determine structure, size, meeting frequency, operating procedures, and guidelines/bylaws.

Size

Smaller groups encourage greater discussion and participation by all members. Most people are more comfortable speaking in a smaller group. It is more challenging to facilitate larger groups and obtain input from everyone. Larger groups will provide a wider range of experiences and input. They also are able to have broader representation of diverse populations. Consider availability of meeting sites to accommodate various sizes of groups. Twelve to eighteen patient and family members is usually considered a manageable size.

Staff membership

No more than 3-4 staff should have a permanent place on the council. Other staff can attend depending on topics for discussion. Staff should have easy access to the council. Too many staff will result in patients/families not feeling it is their council.

Terms of membership

Consider length of term with rotation being intermittent rather than everyone turning over at once. Suggested term is 2-3 years to maintain some consistency. When their term ends they can serve as advisors in other ways such as faculty for staff education or on board level committees.

Compensation/reimbursement

Plan for compensation of time, expertise, and expenses for patients and families. Consider remuneration for patients and families in the form of a small amount to cover transportation expenses, internet or data plans, child or respite care, or other costs that might be incurred. Some patients and families may have difficulty joining the council if they are not given some assistance. Consider providing child care during meetings if needed. Designate one staff member from the organization to be responsible for reimbursement and other practical or logistical issues for family advisors.

Officers

Co-chairs and a secretary are the essential officers. If possible provide organizational support to assist with mailing or emailing materials, distributing minutes. Co-chairs could be two patient or family advisors or a staff person and patient/family advisor. Suggest selecting one new co-chair each year so there is carryover to the next year.

Committees

You may want to create some permanent committees that could include membership of patients/family members who are not on the council. Task forces or ad hoc committees might be identified to work on a specific issue or short-term project. Patients and family members who are not on the council would be encouraged to participate—this will increase the number of patients and family members who participate and provide input as well as help in recruiting long-term advisors.

Guidelines/Bylaws

Operating guidelines/bylaws need to be developed by the council. These are important because they provide the framework for perceived goals and objectives. They also legitimize the group and help promote a feeling of an established, well-organized group. Developing guidelines/bylaws can be time consuming, however, reviewing examples from existing advisory councils can save you time. They can be adapted and amended to suit your group's specific needs.

Select a small core group from the council to develop the guidelines/bylaws. Among the issues that should be addressed in the bylaws are:

- Purpose of the council
- Vision or mission statement
- Goals and responsibilities
- Structure of the council
- Size of the council
- Membership qualifications
- Nominations and elections of members and officers
- Duties of members and officers
- Committees and task forces
- Voting procedures
- Meetings including options for participation (e.g., virtually)
- Agendas
- Expectation for annual assessment of members and council
- Guidelines of authority
- Confidentiality and Privacy
- Leave of absence and termination policies

After developing your group's guidelines/bylaws, present them to administration for approval. All council members should review, discuss, and amend if necessary and give final approval. The guidelines/bylaws should be reviewed annually and revised as necessary.

▼ Meetings schedule

Frequency - monthly is highly recommended. When meetings are less frequent, members lose momentum and involvement and less work can be accomplished. When they are too frequent, members will have trouble attending.

Days/times - let the council members select but may be dependent on room availability if meeting in-person. Consider what is convenient for patients/families and staff.

Agenda

The council should develop a list of issues they wish to work on and “own” the agenda. Staff or other patients/families can add to the agenda. Keep in mind that effective and productive councils are those that align their goals with the strategic priorities of the organization.

Minutes

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

▼ Orientation of new council members

Orientation should include:

- Introductions and the sharing of personal and family stories of health care experiences
- The vision and goals of the organization
- The role of the council, how it fits within the organization’s structure, and how it can assist the organization in achieving its vision and goals
- The roles and responsibilities of members
- The roles and responsibilities of officers
- HIPAA and expectations for honoring privacy and confidentiality
- Meeting attendance expectations of members
- The roles and responsibilities of staff on the council
- How to be an effective council member
- How to present issues effectively
- How to be most effective in collaborating with organizational leaders, clinicians, and staff.

▼ Maintaining history

It is important to track accomplishments and disseminate widely. Track issues the council is working on so they do not get lost.

▼ Sustaining the council

- Invest in building leadership skills of council members
- Select patients and families wisely
- Ensure that the council is representative of patients and families served
- Maintain balance between new members and committed members with longevity of service
- Devote time to planning and evaluation of council efforts and impact
- Set priorities and focus efforts on meaningful collaborative projects

▼ Resources

For a more comprehensive resource see: Minniti, M. M., & Abraham, M. R. (2013). *Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons*. Bethesda, MD: IPFCC.

For guidance to help patient and family members prepare to be an advisor see: Abraham, M., Ahmann, E., & Dokken, D. (2013). *Words of Advice: A Guide for Patient, Resident, and Family Advisors*. Bethesda, MD: IPFCC.

Available for download on IPFCC's website are the following resources:

Diverse Voices Matter: Improving Diversity in Patient and Family Advisory Councils at www.ipfcc.org/resources/Diverse-Voices-Matter.pdf

Key Learnings for Strengthening Partnerships: Recommendations from a National Study of Patient and Family Advisory Councils in U.S. at www.ipfcc.org/resources/IPFCC_Key_Learnings.pdf

Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals at www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf