The Patient and Family Advisory Council Charter

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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.
- Provides an opportunity for patients and families to actively participate in the development of new facilities and programs.
- Channels information, needs, and concerns to staff and administration.
- Actively helps implement changes.
- Provides input into the educational program for staff.
- Collaborates as partners with staff, physicians, and administration in the planning and operation of specific programs.
- Provides opportunities for staff to listen to their customers.
- Provides a safe venue for patients and families to provide input in a setting where they are receiving care.
- Serves as a coordinating mechanism for patients and families.

▼ Benefits of an Advisory Council

- Provides an effective mechanism for receiving and responding to consumer input.
- Results in more efficient planning to ensure that services really meet consumer needs and priorities.
- Leads to increased understanding and cooperation between patients and families and staff.
- Promotes respectful, effective partnerships between patients and families and professionals.

Developed by Marlene Fondrick and Beverley H. Johnson, Institute for Patient- and Family-Centered Care, Bethesda, MD, 1998. Revised 2002

- Offers a forum for developing creative, cost-effective solutions to problems and challenges faced by the program or organization.
- Supplies a link between the program, its surrounding community, and community groups.
- Provides increased emotional support and access to information for patients and families.

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 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 illness, families, and programs utilized. Include families who have had a broad range of experiences. 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.

Identify patients, families, staff, and community organizations that can recommend potential members. Patient representatives, child life personnel, physicians, nurses, managers, and social workers as well as other professionals often are able to recommend candidates.

▼ 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.

▼ Recruitment

- Ask staff for suggestions.
- Post and advertise within the units or clinics.
- Put notices in 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. The workgroup is a quick way to get patient and family participation in hospital 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. The 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. The 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 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.

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 travel expenses, baby-sitting, 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 you cannot provide babysitting service, develop a group understanding about whether or not to bring children to the meeting. Designate one staff member from the hospital or facility to be responsible for reimbursement and other practical or logistical issues for family advisors.

Officers

Co-chairs and secretary are the essential officers. If possible provide organizational support to assist with mailings, etc. Co-chairs could be two patients or family members or a staff person and patient/family member. Suggest selecting one new co-chair each year so there is carryover to the next year.

Committees

May want to have some permanent committees that could include membership of patients/family members who are not on the council. These might be recruitment, communication, etc. Task forces or ad hoc committees might be identified to work on a specific issue or short-term project. Patients who are not on the council would be encouraged to participate—this will increase the number of patients who participate and provide input.

Bylaws

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

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

- Purpose of the group
- Goals and responsibilities
- Structure of the group
- Size of the group
- Membership qualifications
- Nominations and elections of members and officers
- Duties of members and officers
- Committees and task forces
- Voting procedures
- Quorum
- Meetings
- Agendas
- Reporting mechanisms
- Guidelines of authority
- Confidentiality
- Amendment procedures

After developing your group's by-laws, present them to the administration for approval. The total membership should review, discuss, and amend if necessary and give final approval.

▼ Meetings

Schedule

Frequency - monthly or quarterly is suggested. Monthly is usually adequate. Less frequent - lose momentum and involvement. Too frequent, members will have trouble attending.

Days/times - let the council select but may be dependent on room availability. Consider convenience of both patients/families and staff.

Agenda

The council should develop a list of issues they wish to deal with and "own" the agenda. Staff or other patients/families can add to the agenda.

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;
- The vision and goals of the organization;
- The role of the council, how its 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; and
- How to be most effective in collaborating with hospital/clinic staff and faculty.

▼ Maintaining History

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

▼ Sustaining the Council

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

▼ Resources

For the most recent references on this topic, please see the Institute's Compendium of Bibliographies at http://www.ipfcc.org/advance/supporting.html.

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