



TIPS FOR GROUP LEADERS AND FACILITATORS ON INVOLVING PATIENTS AND FAMILIES ON COMMITTEES AND TASK FORCES

Selecting Patients and Families to Serve as Advisors

- ◆ Look for people who are:
 - interested in the topic being addressed by the committee or task force;
 - comfortable in speaking in a group with candor;
 - able to use their personal experience constructively; and
 - able to listen and hear differing opinions.
- ◆ Having just one patient or family member on a committee is not usually successful. Strive for patients and family members to be one-third to one-half of the committee's membership.
- ◆ Remember that serving as a patient or family advisor is a new role for many people. Some patients and family members will need more support than others. Recognize that individuals can grow and develop in this role.

Preparation for Meetings

- ◆ Consider the convenience and schedules of patients and families as well as staff in planning the times and locations for meetings.
- ◆ Send agenda and minutes ahead of time to all committee members, remembering to allow time for material to reach patients and families (they may not have fax machines, email, etc.).
- ◆ Provide a list of committee members with a brief description of each person.
- ◆ Offer a mentor, an experienced patient or family advisor or another committee member, to support a new advisor.
- ◆ Offer to have someone come to the first meeting with a new member and debrief afterwards.
- ◆ Remember that this type of collaboration is new for many people so preparation and orientation is important for staff, as well as patients and family members.

- ◆ Plan for compensation of time, expertise, and expenses for patients and families. For some this may not be necessary. Often just a small stipend is needed to cover mileage and parking.
- ◆ Designate one staff member to be responsible for reimbursement and other practical or logistical issues for patient and family advisors.

During Meetings

- ◆ Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.
- ◆ Provide clear information about the purpose of the committee or task force and the roles and responsibilities of individual members.
- ◆ As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together how to work in new ways. Convey that it will be important for the group to discuss how the process is working from time to time.
- ◆ Avoid using jargon. Explain technical terms when used.
- ◆ Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.
- ◆ Acknowledge that there will be tensions and differing opinions and perceptions.
- ◆ Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- ◆ To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.
- ◆ If a personal story becomes very prolonged, acknowledge the power and importance of the story, suggest that some policy implications can be learned from the story and that there may be other more appropriate forums where this story should be shared.
- ◆ When there are extreme differences in opinions or perceptions, consider:
 - appointing a task force for further study of the issue;
 - asking the opinion of other groups (e.g., another committee or patient/family advisory group); or
 - delaying a decision and considering at a future meeting.

Anticipate Illness Demands

- ◆ Patients and family members may not be able to attend every meeting. There are other demands on their time and stamina.
- ◆ Acknowledge to patients and families themselves and to the committee as a whole that their presence was missed and their participation is valued when they are able to participate. Mailing the minutes and future agendas helps reinforce that their participation is valued.

- ◆ Having shared memberships for patients and family members on the committee may help.
- ◆ Consider having a “patient and family leave policy” so that consumers can choose an inactive role but maintain their membership should there be circumstances that require some time off.
- ◆ Creating a variety of ways for patients and families to participate in the consideration of issues may be useful (e.g., conference calls, written review of materials).