



INSTITUTE FOR FAMILY-CENTERED CARE

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SELECTING, PREPARING, AND SUPPORTING PATIENT AND FAMILY ADVISORS

As clinics, hospitals, and community-based ambulatory practices increase efforts to partner with patients and families in redesigning their programs and policies, they are asking patients and families to serve on committees, task forces, and project teams. Appropriate selection, preparation, and support of patient and family advisors are key to effective partnerships.

SELECTING PATIENT AND FAMILY ADVISORS

A patient or family advisor is an individual or family member who has experienced care in a clinic or hospital and who has experience living with a chronic condition. They should also be skilled in self-management. In identifying patient and family advisors, look for individuals who have demonstrated an interest in partnering with providers in their care or the care of their family member. Consider those who have offered constructive ideas for change and who have a special ability to help staff and physicians better understand the patient or family perspective.

Seek individuals who are able to:

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

To find individuals with these qualities and skills, ask physicians and other clinicians for suggestions. Reviewing the patient registry or their panel of patients may help clinicians identify potential advisors. Community outreach workers, promotores and other lay health workers, and current patient and family advisors may also be able to identify potential advisors. Contacting

support groups and chronic care group education programs is another way to find individuals who might be interested in serving as advisors.

INFORMING POTENTIAL PATIENT AND FAMILY ADVISORS ABOUT ROLES AND RESPONSIBILITIES

Before individuals can make decisions about whether they wish to participate on a quality improvement team or in other health care redesign initiatives, they should be informed of the responsibilities and privileges associated with the role. A fact sheet, containing the following information, can be prepared and offered to individuals who are being asked to participate:

- Mission and goals of the project.
- Expectations for their participation.
- Meeting times, frequency, and duration.
- Travel dates.
- Expectations for communication among team members between meetings.
- Time commitment beyond meeting times.
- Compensation offered.
- Benefits of participation (i.e., what are the expected outcomes of their involvement).
- Training and support to be provided.

COMPENSATION

At a minimum, the program should reimburse patients and families for expenses incurred in association with their work with the team (e.g., parking, transportation, child care). Many programs also offer stipends or honoraria for participation in meetings. These payments typically range from \$12 - \$25 per meeting. Consider the needs of the patient or family advisor and ask about their preferences. If they have no means to cash a check, stipends will have to be offered in an alternative way (e.g., store voucher, cash, etc.).

PREPARING AND SUPPORTING PATIENT AND FAMILY ADVISORS

In order for patients and families to participate effectively as advisors, orientation, training, preparation, and support should mirror that which is offered to staff and physicians. Patient and family advisors should have a chance to discuss their questions or thoughts about the work with the staff liaison who coordinates activities with advisors.

The orientation for patient and family advisors should include information on the following:

- The mission, goals, and priorities of the clinic, community-based ambulatory practice, or hospital.
- Patient- and family-centered care.
- Collaborative self-management support.
- Quality improvement methodology.

- HIPAA and the importance of privacy and confidentiality.

If the organization has a volunteer program, its orientation and training may be very useful for patient and family advisors. Other training issues to consider include:

- Speaking the organization’s language, “Jargon 101.” While it is best to reduce the amount of jargon used in collaborative endeavors, sometimes it is impossible to completely eliminate jargon. If there are terms that will be used frequently in meetings, make sure that patient and family advisors understand them. Encourage them to ask for an explanation of anything they don’t understand.
- Who’s who in the organization or on the project team and how to contact team members.
- How to prepare for a meeting: what to wear, what to do ahead of time, and what to bring.
- How meetings are conducted: format, agenda, minutes, roles (e.g., secretary, timekeeper).
- Training for any technologies that will be used (e.g., conference calls, web-based tools).
- Communicating collaboratively:
 - Expressing your perspective so others will listen.
 - How to ask tough questions.
 - What to do when you don’t agree.
 - Listening to and learning from the perspectives of others.
 - Thinking beyond your own experience.
- How to prepare for any conferences, seminars or other events: making travel arrangements, all logistical information (e.g., hotel, transportation from airport to hotel), expenses that are covered, reimbursement procedures, what to wear, what to bring, and how to prepare for the session. Some patients and families may not have credit cards and therefore will have difficulty in making travel arrangements and will need assistance in planning travel and checking in to a hotel.

It is extremely helpful for new patient and family advisors to have a “coach” or mentor who can provide informal ongoing support to them. A member of the team who has experience working on collaborative initiatives (either a staff person or an experienced patient/family advisor) can be assigned to this role. This person can insure that patient and family advisors are prepared for each meeting. During meetings, this person can also actively encourage participation of the advisor. Also they can debrief after each meeting to determine what

additional information or resources patient and family advisors need. Most importantly, they can support patient and family advisors in participating fully on the team by providing feedback and encouragement.

BELIEVE PATIENT AND FAMILY PARTICIPATION IS ESSENTIAL

The single most important guideline for involving patients and families in advisory roles is to believe that their participation is essential to the design and delivery of optimum care and services. Without sustained patient and family participation in all aspects of policy and program development and evaluation, the health care system will fail to respond to the real needs and concerns of those it is intended to serve. Effective patient/family/provider partnerships will help to redesign health care and advance patient- and family-centered collaborative self-management support. It will lead to better outcomes and enhance efficiency and cost-effectiveness. Providers will also discover a more gratifying, creative, and inspiring way to practice.

The tool, “Patients and Families as Advisors: A Checklist for Attitudes,” can be used to help physicians and staff assess their own attitudes and beliefs about partnerships with patients and families.

This material has been adapted from two resources: *Developing and Sustaining a Patient and Family Advisory Council* and *Essential Allies: Families as Advisors* published by the Institute for Family-Centered Care.

For additional information and guidance resources available through the Institute for Family-Centered Care:

Webster, P. D., & Johnson, B. H. (2000). *Developing and sustaining a patient and family advisory council*.

Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating patient and family faculty programs*.

Blaylock, B. L., & Johnson, B. H. (2002). *Advancing the practice of patient- and family-centered geriatric care*.

Thomas, J., & Jeppson, E. S. (1997). *Words of advice: A guidebook for families serving as advisors*.

Conway, J., Johnson, B. H., Edgman-Levitan, S., Schlucter, J., Ford, D., Sodomka, P., & Simmons, L. *Partnering with patients and families to design a patient- and family-centered health care system: A roadmap for the future—A work in progress*. Retrieved November 27, 2006 from <http://www.familycenteredcare.org/pdf/Roadmap.pdf>.

For additional information about building partnerships with patients and families, visit the following websites:

Institute for Family-Centered Care: Advancing the Practice: Patients as Advisors and Leaders at <http://www.familycenteredcare.org/advance/pafam.html>.

New Health Partnerships at <http://www.newhealthpartnerships.org>.

Available from the Joint Commission on Accreditation of Healthcare Organization:

McGreevey, M. (Ed.). (2006). *Patients as partners: How to involve patients and families in their own care*. Oakbrook, IL: Joint Commission Resources, Inc.