PATIENTS AND FAMILIES AS ADVISORS IN PRIMARY CARE: BROADENING OUR VISION

There are countless ways that patients and families can serve as advisors to health care providers, staff, and administrators. Some are formal and ongoing, others are time limited and informal. All will help ensure that the system of care is centered on patient and family needs, strengths, priorities, goals, and values. Below is a list of some of the ways that patients and families can serve as advisors in ambulatory care.

**Short-Term or Long-Term**

Participate in surveys, focus groups, brainstorming sessions, work groups, teams...

- Conduct follow-up phone calls with patients and families after visits to gather their perspectives on the experience of care
- Hold quarterly or semi-annual coffee hours with patients and families to explore ideas for improving care
- Hold brainstorming sessions with patients and families to develop and revise:
  - Brochure/video for clinic or practice
  - Website content
  - Patient educational materials
- Ask patients and families to assist in adapting patient information materials to meet literacy and language needs of community served
- Gather ideas from patients and families about helpful community programs

**Long-Term**

Participate in/facilitate teams, work groups, councils, and as staff...

- Create an advisory council of patients and families who receive care at the ambulatory practice
- Invite patients and families to serve as members of state or national learning and improvement collaboratives
- Include patients and families on teams to plan, conduct, and evaluate group visits
- Offer opportunities for patients and families to lead or co-lead educational and support programs (e.g., self-management of chronic conditions, peer to peer support)
- Prepare patients and families to provide education to providers and staff through:
  - Panel discussions/role playing activities during new employee orientation and ongoing inservice
  - Shadowing programs
  - Home/community visits for students and professionals in training
<table>
<thead>
<tr>
<th>Short-Term or Long-Term</th>
<th>Long-Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participate in surveys, focus groups, brainstorming sessions, work groups, teams...</td>
<td>Participate in/facilitate teams, work groups, councils, and as staff...</td>
</tr>
</tbody>
</table>

- Appoint patients and families to teams and work groups related to:
  - Medical home/health home initiatives
  - Waiting room activities, registration procedures, clinic flow
  - Medication management
  - Care coordination
  - Documentation systems, electronic health records
  - Integrating behavioral health into primary care
  - Choosing Wisely

- Invite patients and families to assist in creating or revising patient/family satisfaction survey or real-time feedback mechanisms

- Include patients and families on site visit teams to other practices

- Ask patients and families to join staff at meetings with:
  - Community groups
  - State lawmakers

**Other ideas:**

Selecting Patients and Families to Serve as Advisors

- Look for people who are:
  - Interested in the topic being addressed by the committee, work group, or team;
  - Comfortable speaking in a group with candor;
  - Able to use their personal experience constructively;
  - Able to bring a broad perspective about the experience of others, and
  - Willing to listen and respond to differing opinions and ideas.
- Having just one patient or family member on a committee is not usually successful. Start with at least two and strive for patients and family members to be one-third to one-half of the committee membership.

Planning and Preparing for Meetings

- Consider the convenience and schedules of patients and families as well as staff in planning the times and locations for meetings.
- Determine what meetings can be conducted virtually (e.g., through conference calls, video calls) and what tasks can be done at home.
- Send materials (e.g., agenda, documents to review) ahead of time to all members, allowing sufficient time for material to reach patients and families.
- Provide a list of members with a brief description of each person.
- Provide information about the committee, work group, or team including purpose, priorities, activities, and outcomes/achievements.
- Explain how meetings are conducted and how decisions are made within the group.
- Offer a mentor—an experienced patient or family advisor or another committee member—to support a new member.
- Meet with each new member before the first meeting to prepare and answer questions and debrief afterwards.
- Prepare staff to work collaboratively with patient and family members. Prior to inviting patients and family members, discuss any concerns they have.
- Plan to cover expenses for such things as transportation or parking. Consider honorariums when expertise or significant time commitment is required.
- Designate one staff member to be responsible for reimbursement and other practical or logistical issues for patient and family advisors.
Conducting Meetings

• Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.

• Acknowledge that collaboration is a process with everyone learning together how to work in new ways and that differing perspectives and opinions are expected. Convey the importance for the group to regularly discuss how the process is working.

• Avoid using jargon. If this cannot be avoided, make sure patients and family members have been prepared or have a glossary of terms they will most likely hear. Encourage members to ask for explanations whenever needed.

• Consider beginning some meetings with a brief story that captures patients and families experiences and perceptions of care that relate to the group’s area of focus.

• If needed, ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as team or group members.

• If a personal story becomes very prolonged or dominates the discussion, acknowledge the power and importance of the story and identify what is helpful to the group. If needed, suggest other forums where this story could be shared.

• To avoid becoming stuck in the power of a negative story, acknowledge the negative experience. If the situation relates to the group’s purpose and priorities, ask for ideas to consider for change and improvement. If it does not relate, refer the person to the appropriate contact person and follow up to make sure it was resolved.

• When there are extreme differences in opinions or perceptions, consider:
  − Appointing a sub-group for further study of the issue
  − Asking the opinion of other groups or staff members
  − Asking for an outside facilitator to assist the group
  − Delaying a decision and considering at a future meeting

• Devote time at the end to evaluate the effectiveness of each meeting.

Sustaining Momentum

• Determine how the group will measure success and conduct regular assessments.

• Communicate accomplishments to leadership, colleagues, patients and families, and the community.

• On an annual basis (for ongoing groups) or at the completion of the effort/project, invite each patient and family member to participate in an individual self-evaluation process.

© 2014 Institute for Patient- and Family-Centered Care
FRAMEWORK FOR PATIENT AND FAMILY INVOLVEMENT IN QUALITY IMPROVEMENT

The following presents a framework for ways to think about including patients and families on quality improvement teams. Overall, as you read through the roles, the level of involvement of patients and families increases with subsequent increases noted in their responsibilities and the means in which they are prepared, compensated, and acknowledged. To minimize repetition in the preparation/compensation/acknowledgement column, the suggestions build on each other (e.g., strategies to consider within one level assumes that an organization would consider the preparation, compensation, and acknowledgement included at all previous levels as well as for that particular level).

<table>
<thead>
<tr>
<th>Roles¹</th>
<th>Responsibilities</th>
<th>Preparation/Compensation/Acknowledgement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients and Families as Participants</strong></td>
<td>Patient and family perceptions of care and quality are elicited and used in shaping improvement initiatives. Data/information from patients and families also used in measuring improvement. Responsibilities for patients and families end when their input is received unless they are asked to provide feedback on the interpretation of the data.</td>
<td>Most programs ask patients and families to provide feedback as a means to measure quality. However, often these measurements are developed by professionals and may fail to insure that what is important to patients and families regarding quality care is being measured. At this level, attention is focused on insuring that the instruments and methods accurately capture patients' and families' experience of care. In keeping with a patient- and family-centered approach, efforts to insure that all patients and families within a program or practice (or a sampling that adequately reflects the diversity of the population served) are included in evaluation activities. In addition, information about the evaluation's purpose needs to be shared with respondents or participants in order for them to make an informed choice about whether or not to participate in the activity. Acknowledgement of appreciation for their participation is necessary. Supplying participants with a summary of the data and information about how the data will be used to improve quality and safety (e.g., at a community meeting, as a written summary, on a website) should also be considered. Developing diverse formats to disseminate information will insure patients and families are able to access and understand the findings.</td>
</tr>
</tbody>
</table>

¹Roles
<table>
<thead>
<tr>
<th>Roles 1</th>
<th>Responsibilities</th>
<th>Preparation/Compensation/Acknowledgement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients and Families as Advisory Board/Council Members 2</strong></td>
<td>If programs create or have an existing patient and/or family advisory board/council, this group can serve as a resource to the quality improvement team. Also, some of the members can be asked to participate directly on the quality improvement team. Responsibilities will depend on level of involvement the advisory board/council is offered. If the advisory board/council is asked to review policies, programs, evaluation methods after staff has determined them then the members have little partnership opportunities. If, however, the advisory board/council assists in the planning, implementation, and evaluation of improvement projects, then its responsibilities will be much greater and the board/council will be viewed as more of a partner than reviewer.</td>
<td>The most effective patient and family advisory boards/councils have established the group’s structure, activities, and methods for evaluating the work. Members typically have gone through an application process and receive training and mentoring to participate on the board. If the council or board will be asked to serve as a resource to the improvement team, then they will require education relating generally to the improvement model used and specifically to the work scope of the improvement team. If members will be asked to serve on the team, they will require preparation described in the fourth level titled, “Patients and Families Serving as Ongoing Advisors/Consultants” (refer to p. 3). Programs may support these patient and family advisory boards/councils by offering space for meetings, administrative support (e.g., mailings, secretarial support, printing costs, etc.). There may be staff members identified to serve as liaisons to the advisory boards (with their time being covered by the program) in order to build communication, coordination, and partnership. In addition, programs show their commitment by including the advisory board within a shared governance model and/or offering regular opportunities for the board to report to senior leadership.</td>
</tr>
<tr>
<td><strong>Patients and Families as Occasional Reviewers and Consultants 2</strong></td>
<td>Patients and families may be asked to review or discuss specific issues at various points in the improvement process. This level offers patients and families flexibility in how they will participate. Depending on the activity, patients and families can review and advise in person, through e-mail or an interactive online forum, over the telephone, or in a written format.</td>
<td>Preparation would be required for patients and families to serve effectively as reviewers and consultants to quality improvement teams. This preparation would obviously be determined by the task. Individual reviewers can receive one-to-one training by a member of the improvement team. If several patients and families will be serving in this capacity, then group training can be offered. If the improvement team already has patients and families involved as ongoing advisors, then experienced patients and families can serve as trainers and mentors for the occasional patient and family reviewer and consultants. Compensation and acknowledgement ideas that should be considered include childcare, meals, parking and other transportation costs associated with their participation, and stipends for participation.</td>
</tr>
<tr>
<td>Roles&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Responsibilities</td>
<td>Preparation/Compensation/Acknowledgement</td>
</tr>
<tr>
<td>------------------</td>
<td>------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td><strong>Patients and Families as Ongoing Advisors/Consultants</strong>&lt;sup&gt;3&lt;/sup&gt;</td>
<td>At this level, patients and families would be seen as having continuous involvement with the improvement team. They would be actively participating as members of the teams who are planning, implementing, and evaluating either individual projects within the program and/or the work of the program's improvement team as a whole.</td>
<td>In order for patients and families to participate at this level, training, preparation, and support would mirror that which is offered to staff participants. They would require training specifically in the improvement model and processes. Expectations for their active involvement would be defined and regularly reviewed. In addition, this level would also require that physicians and staff members of the team receive training in working collaboratively with patients and families.&lt;sup&gt;5&lt;/sup&gt; Since this involves a higher level of commitment on the part of a patient and family member, reimbursement for time and travel should be offered. In addition, to support them in playing an active role, other issues such as childcare, transportation costs, parking, meals, etc. should be planned for. Programs should also consider hiring a patient or family member to work with the quality improvement team.</td>
</tr>
<tr>
<td>- Active task force or committee members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Faculty for staff education&lt;sup&gt;4&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Participants at collaborative meetings/conferences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Roles¹</td>
<td>Responsibilities</td>
<td>Preparation/Compensation/Acknowledgement</td>
</tr>
<tr>
<td>--------</td>
<td>------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Patients and Families as Co-Leaders</td>
<td>This represents a very high level of involvement for a patient and family member and therefore the role requires adequate skills and knowledge. Previous work/education is obviously valuable. However, in order to bring voices that represent typically underserved populations, community leadership experiences can be considered. Also, experience serving as an effective advisor within the practice or program can offset a lack of relevant professional/educational experience.</td>
<td>This level does require preparation included in all previous levels as well as additional preparation in order for patients and families to effectively collaborate with staff and physician leaders. It would also require supervision and evaluation. Because of the requirements, commitment, and role expectations it is advisable that patients and families are hired as staff/consultants to serve in these positions.</td>
</tr>
<tr>
<td>• Facilitator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Content expert</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Evaluator⁵</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Faculty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Author</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

These are ideas for consideration. Mutual trust and respect must be built no matter what level patients and families are serving within. This takes time. As teams offer patients and families more opportunities to participate, time spent in building an understanding of individual areas of expertise and common goals will help strengthen a team's capacity to collaborate.

Marie Abraham, MA  
Policy and Program Specialist  
Institute for Family-Centered Care

Julianne Nickerson, MSW  
Family Leader  
Family Faculty Director  
Parent-to-Parent Vermont  
Burlington, VT

Notes

¹The framework for the roles was adapted from an article on participatory action research by Turnbull, Friesen, Ramirez, 1998 (see references).

²For a comprehensive resource on family advisory boards, refer to Webster & Johnson, 2000 (see references).

³Refer to Dillon, 2003 (see references) for a guidance on parent participation on quality improvement teams.

⁴Refer to Blaylock, Ahmann & Johnson, 2002 (see references) for a resource on patients and families as faculty.

⁵Refer to Abraham, Ahmann, & Dokken, 2013; Minniti & Abraham, 2013; and Turnbull, et al., (see references).

⁶For an annotated bibliography of families serving on evaluation teams refer to Jivanjee, et al., 2004 (see references).
Resources

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


### PARTNERING WITH PATIENTS AND FAMILIES TO ACCELERATE IMPROVEMENT READINESS ASSESSMENT

**Name of Organization______________________________**

<table>
<thead>
<tr>
<th>Area</th>
<th>For each item, circle the box that best describes your team’s perspective and experience.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data transparency</strong></td>
<td>Our team is uncomfortable with the possibility of sharing performance data with patient and family members.</td>
</tr>
<tr>
<td><strong>Flexibility around aims and specific changes of improvement project</strong></td>
<td>We have limited ability to refine the project’s aims or planned changes.</td>
</tr>
<tr>
<td><strong>Underlying fears and concerns</strong></td>
<td>We have identified several concerns about involving patient and families on improvement teams and would need assistance in creating a plan for addressing them.</td>
</tr>
<tr>
<td><strong>Perceived value and purpose of patient and family involvement</strong></td>
<td>There is no clear agreement that patient and family involvement on improvement teams is necessary to achieve our current improvement aim.</td>
</tr>
</tbody>
</table>
### Senior leadership support for patient and family involvement

| Senior leaders do not consider patient and family involvement in improvement a top priority. | Senior leaders are aware of and communicate support for patient and family involvement in our team. | Senior leaders consider our participation in this project as a pilot for organizational spread of patient and family involvement as advisors in improvement. |

### Experience with patient and family involvement

| Beyond patient satisfaction surveys or focus groups our organization does not have a formal method for patient and family feedback. | We have an active patient and family advisory panel. | Patient and families are members of standing committees and make decisions at the program and policy level. |

### Collaboration and teamwork

| Staff in this organization occasionally work in multidisciplinary teams to provide care. | Staff in this organization work effectively across disciplines to provide care to patients. | Staff are effective at working collaboratively in multidisciplinary teams that include patients and families as valued members of the care team. |

1. What supports moving in the direction of involving patients and families?
2. What are your current challenges?
3. How confident are you on successfully involving patients and families on your team (on a 1-10 scale with 1 = not confident at all and 10 = extremely confident)? ________

© 2007 Adapted from a tool developed in collaboration between the Cincinnati Children’s Hospital Medical Center and the Institute for Healthcare Improvement for Web & ACTION: Partnering with Patients and Families to Accelerate Improvement.