Working With Patient and Family Advisors

The benefits of working with patient and family advisors

Bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of care is a critical part of improving safety and quality.

After hearing from patient and family advisors, clinical staff at BIDMC have said that their professional practice will change as a result.

In what ways?

• More attuned to patient input

• How I approach how I answer patient questions, and encourage them to ask questions

• Better explain the "why" behind what I am explaining, as well as being more open-ended vs. just giving instructions, in order to help patients feel empowered

Patient and family advisors:

- Offer insights that illustrate what we do well and highlight where changes may be needed
- Help us develop priorities and make improvements based on patient- and family-identified needs rather than on our own professional assumptions
- Bring a fresh perspective and help us come up with solutions that clinicians and staff have not yet thought about

Working with advisors helps build a shared agreement around safety and quality priorities. This shared agreement fosters partnerships in care, enhances the care experience, and improves outcomes.

Nurse Managers at BIDMC have wanted to work with advisors because…

"We're looking for patients to tell us what we are doing well and what we could do better to best serve them."

"I'm hoping to open the dialogue with patients/families."

Working with advisors is part of patient- and family-centered care

Patient- and family-centered care emphasizes collaboration with patients and families at all levels. The core concepts of patient- and family-centered care are:

- Dignity and respect. Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- Participation. Patients and families are encouraged and supported to participate in care and decisionmaking at the level they choose.
- Information sharing. Patients and families receive timely, complete, and accurate information to effectively participate in care and decisionmaking. Clinicians and hospital staff communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
- Collaboration. Patients, families, clinicians, hospital staff, and health care leaders collaborate in policy and program development, implementation and evaluation, facility design, professional education, and the delivery of care.

Ways to get started working with patient and family advisors

There are countless ways that you can partner with patient and family advisors. Getting started often involves small steps, such as working with advisors on one specific issue or project. Below are examples of ways that others at BIDMC have worked with patient and family advisors.

- The voice of the customer. Asking a group of patients and family members to share what went well, what could have gone better, and what ideas they have for change and improvement.
- Feedback on educational or informational materials, such as patient and family handbooks, instructions for home care after a hospital stay, or care transition instructions. Often patients and families point out details that are important from their perspective that might not be noticed by staff.
- The face of a real patient or family member in a video project, to share their perspectives on care and how illness or hospitalization affects patients and families.
- Walking through a unit or waiting room with patient and family eyes to explore how a unit welcomes patients and families and encourages their participation in care and decisionmaking. Patients and families have shared their perspectives on the admitting area, patient rooms, treatment rooms, the family lounge, and other areas visible to patients and families.

Key questions to consider before working with patient and family advisors

- What is the goal of seeking patient and family input and feedback?
- What will be the end result or product of the input/feedback?
- What are some questions you would like to address through your use of patient/family advisors?
- Who is on your team and should know about this project? Who are the key stakeholders or major players? Is there an executive sponsor?
- What is the ideal timeframe for this project?
- What resources currently exist to be applied to this project – financial and staff time?
- Have patient/family advisors been used in the past? In what ways/for what projects?

Principles for effective partnership

- Define a clear role for advisor participation
    - Provide opportunities to contribute where advisors can make a tangible difference
- Give information about the purpose, goals, and intended outcomes of the effort
- Clearly define expectations, including timelines, deadlines, and responsibilities
- Designate a staff member or key contact for working with patient and family advisors
- Provide background information on the project
    - Avoid acronyms and jargon whenever possible
- Invite participation
- Listen with an open mind

Group Facilitation With Patient and Family Advisors

Getting started: Logistics and Recruitment

Logistics

When will the group meet?

- What time of day works best for group members and is most likely to lead to engaged participation and regular attendance?

Where will the group meet?

- Should the meeting take place at the medical center or in a community based location?
- What kind of room is best?
- How will chairs be arranged?
- Does space need to be reserved?

How often will the group meet?

- Some groups meet more often in the beginning and meet less frequently after the group members have gotten to know each other and understand the purpose of the group and their roles.

  ex: every month for the first 3 months and then every other month

For how long will the group meet?

- What are the goals of the group and will they be accomplished in the short term, or is it more appropriate for the group to meet for a longer period of time?

Recruitment

Who is in the group?

What are inclusionary criteria?

- Are there particular experiences that you want group members to share?
- Is there a time frame that is relevant to the group (such as being a patient within the last year)?
- Are there particular characteristics that you want to use in recruitment, such as age, gender, racial, ethnic diversity, or type of treatment?

What are exclusionary criteria?

- Is there a particular experience or characteristic that you don't want group members to have?

Is membership open or closed?

- If a group is in development but it is important to start meeting before the group is "full," it may be appropriate to keep the group open. It will be important to communicate to group members that the group is open and will accept/invite new members. Similarly, it is important to communicate to the group when the group is "closed" to new members.

What do members need to know to be prepared for membership?

- Generally, members want to know about logistics, which ideally are determined before the group begins meeting.
- Decide how much the group will focus on process and how much on solutions.

  Will there be any work between meetings?

Moving forward: Stages of group development

1. Forming

   Members first get together during this stage. Individually, they are considering questions like, "What am I here for?", "Who else is here?" and "Who am I comfortable with?" It is important for members to get involved with each other, including introducing themselves to each other. Clear and strong leadership is required from the team leader during this stage to ensure the group members feel the clarity and comfort required to evolve to the next stage.

2. Storming

   During this stage, members are beginning to voice their individual differences, join with others who share the same beliefs, and jockey for position in the group. Therefore, it is important for members to continue to be highly involved with each other, including to voice any concerns in order to feel represented and understood. The group leader should help members to voice their views, and to achieve consensus (or commonality of views) about their purpose and priorities.

3. Norming

   In this stage, members are beginning to share a common commitment to the purpose of the group, including to its overall goals and how each of the goals can be achieved. The group leader should focus on continuing to clarify the roles of each member, and a clear and workable structure and process for the group to achieve its goals.

4. Performing

In this stage, the group is working effectively and efficiently toward achieving its goals. During this stage, the style of leadership becomes more indirect as members take on stronger participation and involvement in the group process. Ideally, the style includes helping members to reflect on their experiences and to learn from them.

5. Adjourning - Closing and Celebration

At this stage, it is clear to members and their organization that the group has achieved its goals (or a major milestone along the way toward the goal). It is critical to acknowledge this point in the life of the group, lest members feel unfulfilled and skeptical about future group efforts.

Source: Adapted from Carter McNamara, MBA, PhD . Authenticity Consulting

How to be a great facilitator at each group stage

1. Forming

Be directive and create structure – the group is looking to you for guidance.

What you can do:

- Bring a written agenda
- Allow group members to get to know each other through structured and purposeful icebreakers
- Clearly define the purpose of the group
- Create a group "contract" or agreement (bylaws, guidelines, ground rules) that defines the expectations for participants
- Be vigilant about setting the frame for the group in terms of starting and ending on time as this structure sets the expectation for the duration of the group

2. Storming

Be accessible, but still maintain your role as a guide. You can create norms within the group about how the group makes decisions and what is considered appropriate behavior in the group. Group members will be able to participate with each other more comfortably, as they will feel that the group is a safe place for them to share their opinions and feedback.

What you can do:

- When members ask questions of the leader, redirect them and engage the group in the discussion
- Remind group members about group ground rules

3. Norming

At this stage, you can turn over some of the responsibility of the group to the group itself – members can take on some responsibility for working toward the group's goals.

What you can do:

- Consider what role the group might have in helping to create the agenda for meetings
- Work with the group to give members more responsibility in meetings (notetaking, co-faciliating)
- Create workgroups that allow group members to work together outside of meetings

4. Performing

All groups do not always reach the "performing" stage, but groups that do are motivated and knowledgeable. The group's need for facilitation has decreased as members' competency and autonomy has increased. Long-running groups will cycle through the stages over time. For example if there is a change in leadership, the group may go back the "storming" stage to define group norms and dynamics.

What you can do:

- Allow the group to direct some of the group's activities
- Provide structure so that the group focuses on and maintains its purpose

5. Adjourning – Closing and Celebration

You can create an opportunity for the group to reflect on its accomplishments and celebrate its successes.

What you can do:

- Plan a closing celebration
- Ask the group to summarize what they think they have accomplished

Specific skills for group facilitation

Asking clarifying questions

Clarifying questions can keep the discussion from getting lost if the group discussion has become too vague, too general, or lacks focus, or when a lot of information has been put out. A facilitator can ask for clarification of an example, build on the ideas of others, clarify an idea based on your understanding, or try to develop timid suggestions and half stated ideas into fully developed possibilities. Asking clarifying questions can help a facilitator get at the question behind the question.

- "What I think I hear you saying is ___"
- "Robert, can you explain your idea a bit more?"
- "Cecilia, do you see how that idea relates to what Luis said earlier?"

Reigning in the conversation

Summarizing can help reign in the conversation and move it in a productive direction. Summarizing involves pulling together related ideas, restating suggestions after the group has discussed them, and offering a decision or conclusion for the group to accept or reject. Reminding the group of the process or method being used for the discussion can be another way to reign things in.

- "Let's take a minute to look at the main themes that are arising in our discussion"
- "It looks like the main points being raised are ___"
- "Remember that each person needs to offer a suggestion before we begin an open discussion."

Using a "parking lot"

Sometimes the group will raise more ideas than can be discussed in one meeting. Using a "parking lot," or visual way to store ideas for the future, can help group members feel heard while helping facilitators stay organized and keep the meeting on track. Creating this tool is as simple as writing the words "Parking Lot" on a sheet of chart paper and putting it up where all group members can see.

Bringing out quiet members

To help keep communication channels open, you can ask a quiet member directly for information or for their opinions, be sensitive to non-verbal signals that people want to participate, and asking others for input when the conversation is being monopolized by one member of the group.

- "Mary, what do you think of that idea?"
- "Jeff, did you want to share something?"
- "Thanks for your input, Robin. I'd like to know what the rest of you think."

You can also remind group members that they can always share additional ideas outside of the group via e-mail or during breaks. As the facilitator, you can then bring those ideas into the group, remembering to give credit to the quiet member who shared the idea.

Source: Adapted from Stanford University's Residential Education Resource Manual

Considerations for group facilitators

Seating and non-verbal communication

Sitting where you can see your co-facilitators and spreading yourselves out around the room is important so that you can communicate with each other non-verbally throughout the group meetings. You might discuss in advance some cues that you could give each other to communicate about timing, last-minute changes in who's facilitating what part of the meeting, or if one of you needs to leave the room unexpectedly.

Spreading yourselves around the room also allows for each of you to see the room from a different vantage point and makes it less likely that you will miss key facial expressions or other non-verbal communications by group members.

Who are you as a facilitator?

Below are some questions to ask yourself as you begin facilitating a group that will help you think in advance about your preferences for dealing with discussions and group dynamics.

- What are my personal beliefs, values and stereotypes about the issue?
- Can I assume an objective role in the discussion?
- What role should I assume as a facilitator?
- How do I establish trust and openness among the group?
- How do I show respect for the opinions of others?
- How do I tactfully mediate conflict?
- How do I keep discussion flowing smoothly?
- How do I encourage the participation of everyone and avoid domination by a few?
- How do I deal with someone showing disrespect for another?
- What should I do when I don't know how to respond to a comment or question?
- Will I feel comfortable facilitating a group discussion on this issue?

Source: Stanford University's Residential Education Resource Manual

Debriefing

- Taking a few minutes to debrief the meeting with your co-facilitator allows for reflection on how things went, themes that emerged, what could have been done differently or needs to be changed for next time, and/or next steps or follow-up actions that need to be assigned.
- It's also a good time to check in about any individuals who did not participate as fully as expected in the discussion so that you can keep an eye on their future participation. Finally, debriefing is an opportunity for facilitators to get feedback from each other on what they did well or what they could improve in their facilitation style or methods.