



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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Learning From Patient and Family Stories – Patient and Family Panels

A patient and family panel presents the opportunity for clinicians and staff to hear directly from patients and families about the experience of care, what is important and helpful to them, and what can be improved. The stories, insights, and perspectives shared by patients and families help clarify and give meaning to the following core concepts of patient- and family-centered care:

- **Respect and dignity;**
- **Information sharing;**
- **Participation; and**
- **Collaboration at all levels of care.**

Patient and family panels assist health care professionals in developing a deeper understanding of, and commitment to, patient- and family-centered care.

This type of panel often begins with patients and families being asked to introduce themselves and to share a brief description about the ways they have used the health care system (e.g., managing diabetes in a primary care clinic, frequent visits to the Emergency Department due to asthma; or hospitalizations for cardiac surgery and community follow-up for rehabilitation).

Effective patient and family panelists are able to share their stories so others can learn from them. They are able to identify positive aspects of health care experiences as well as help the audience appreciate the opportunities for improvement. They are also capable of speaking candidly in front of an audience. By carefully preparing to tell their stories, patient and family panelists stimulate open discussion of current policies and practices rather than defensiveness.

In preparing for a panel, think about an experience or two when you left the clinic, hospital, or another health care encounter, that you felt was a very good experience. It “worked” for you or your family. It meant that you or your family:

- Were treated in a welcoming, supportive, and encouraging manner;
- Got the information you needed in ways that were understandable and useful;
- Were included in decision-making;
- Were respected for your knowledge; and/or
- Felt that you were valued and that your goals, preferences, and priorities were incorporated into care planning.

Then also think of an experience or two that demonstrates where things didn’t work so well. You or your family:

- Did not feel respected;
- Were not included in discussions about your care, concerns, and priorities;
- Were not valued for your input;
- Were not given time to demonstrate your knowledge or ability; and/or
- Were not included in decisions and the timelines or schedules were staff-centered, not patient- and family-centered.

Some panels explore how patients and families have served as advisors, what has been helpful to them in being effective in these roles, and why this work is important to them. You might be asked to describe such experiences as the following:

- Serving as a member of a quality improvement team or a committee to redesign clinic policies and practices;
- Participating in planning a renovation or new construction project for a clinic or hospital;
- Orienting new staff and clinicians or helping enhance their communication skills;
- Assisting in creating new charting and documentation systems or personal health records; or
- Developing information and education materials.

Usually, the panel facilitator will contact you prior to the panel to help you prepare for sharing your story and let you know what to expect.

Try to keep your stories and descriptions of experiences somewhat brief so everyone on the panel has a chance to share. There is usually time to tell more stories or expand the stories once everyone has shared. Feel free to bring notes, pictures, etc. – anything that will help you remember what you want to talk about. Usually the audience is asked if they have questions for the patients and families on the panel. If you feel uncomfortable with a particular question, you can always decline to answer a question.

Remember, some of the stories may bring emotions to the forefront that you have not experienced for a while. That is okay – just don't be surprised if you are touched by others' stories or stories remind you of something in your own experiences. The panelists and the audience are touched also. These panels are typically powerful opportunities for clinicians and staff to connect with the patient and family experience, see the impact they have on patients and their families, and consider changes they can make in their own practice.