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 (i.e., 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).

Roles[1]	Responsibilities	Preparation/Compensation/Acknowledgement
Patients and Families as Participants •Respondents to surveys and other evaluative activities •Focus group members	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.	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 (i.e., at a community meeting, as a written summary, on a Web site) should also be considered. Developing diverse formats to disseminate information will insure patients and families are able to access and understand the findings.

Roles[1]	Responsibilities	Preparation/Compensation/Acknowledgement
Patients and Families as Advisory Board/Council Members[2]	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.	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.
Patients and Families as Occasional Reviewers and Consultants[2]	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.	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.

Roles[1]	Responsibilities	Preparation/Compensation/Acknowledgement
Patients and Families as Ongoing Advisors/ Consultants[3] •Active task force or committee members •Faculty for staff education[4] •Participants at collaborative meetings/ conferences	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.	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.[5] 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.

Roles[1]	Responsibilities	Preparation/Compensation/Acknowledgement
Patients and Families as Co-Leaders • Facilitator • Content expert • Evaluator[6] • Faculty • Author	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.	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. 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.

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

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

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

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

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

[5] Refer to Jeppson, Thomas, 1995, 1997 and Turnbull, et al., (see references).

[6] For 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 the Institute's *Compendium of Bibliographies* at http://www.familycenteredcare.org/advance/supporting.html

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