

Nothing About Me without Me

Including Patients in QAPI and Governing Body Meetings

The Department of Health and Human Services National Quality Strategy's new focus on better care for the individual through beneficiary- and family-centered care involves working **with** patients rather than doing **to** or **for** patients. Such partnerships are mutually beneficial to the patients and the facility. Involving patients in your facility's Quality Assurance & Performance Improvement (QAPI) and/or Governing Body meetings can be an effective means of engagement and partnership. Below are some ideas for getting started.

Before the Meeting

Select the Patient/Family

- Look for individuals who have demonstrated **interest in partnering** with you in their care or care of a family member.
- Consider those who have offered **constructive ideas** for change and have a special ability to help staff and physicians better understand the patient perspective.
- Seek individuals who can:
 - **Share insights** about their experiences in ways that others can learn from.
 - **Listen** well.
 - **Respect** the perspectives of others.
 - **Speak comfortably** in a group with candor.
 - Show a **positive** outlook on life and have a sense of humor.
 - Work in **partnership** with others.

Invite the Patient

- Invite the patient but do so out of earshot of other patients.
- Share the **purpose** of the meetings and **why** they are being invited.
 - Use patient-friendly language/no jargon.
 - Make it personal: "We've noticed that you interact well with other patients and have a real interest in your care, the facility, and what goes on here..."
- Review the patient's **role** in the meetings. Let them know if he/she is attending:
 - In an advisory, ad hoc, or non-voting member capacity.
 - To offer suggestions for improved patient involvement with ideas and strategies for improved care.
 - To share his or her experience with other patients, if they are comfortable doing so.
- Provide information on **topics** usually covered in meetings and answer any questions the patient might have.
- Consider the patient's availability when **scheduling** meetings.
- **Provide the invitation in writing** with the meeting date, time, and location.
- Request that the patient inform you (RSVP) if they will be participating by a certain date.
- If the patient says they will participate:
 - **Provide the patient** with the *QAPI Patient & Family Meeting Notes*.
 - **Educate patient** on topics covered.
 - **Ask** if he or she has any questions.

Staff Preparation

- Go through ALL reports that will be reviewed while the patient is present and **remove any patient-identifying information**.

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- Each discipline should evaluate/prepare the report with open-ended, **directed questions** for the patient.
 - What would be the best way to (fill in the blank)?
 - Based on this report, what did you hear that was important and how do you suggest that we assist patients with that?
 - From your perspective, what are challenges to starting a new (fill in the blank)?
 - From your perspective, what are challenges to changing (fill in the blank)?
 - What do you think is the best way to approach (fill in the blank)?
- **Staff should remind the patient about the meeting** beforehand and to bring their *QAPI Patient & Family Meeting Notes*.

During the Meeting

- **Introduce** all members by name and role.
- **Welcome** the patient and either ask them to introduce themselves or make the introduction for the patient.
- Review what **confidentiality** means in the meeting setting.
 - Observe all Health Insurance Portability and Accountability Act of 1996 (HIPAA) rules and regulations.
 - Do not refer to other patients by name.
 - Do not discuss any case- or patient-specific details.
- **Don't use jargon or acronyms.** Use patient-friendly language when reviewing reports and data.
- **When setting the agenda,** set aside time early in the meeting to discuss topics of interest to the patient and/or items on which the staff would like patient feedback or insight.
- **When using graphs or charts,** orient all who are present about what the graph or chart means or is showing. This way the patient will not feel singled-out.
- **Solicit patient/family input.** Direct questions to the patient, such as:
 - What would be the best way to?
 - Based on this report, what do you think are important next steps toward improving patient experience of care or outcomes?
 - From your perspective, what are some challenges or barriers to?
- **Document patient attendance/participation.** Include the patient advisor's attendance and participation in committee meeting minutes.

After the Meeting

- Include patient attendance and participation in meeting minutes.
- Follow-up with patient directly on any hot-topic issues prior to the next meeting.
- **Follow-up with the patient about their experience before, during, and after the meeting.**
 - Would he/she be willing to participate in future QAPI/Governing Body meetings?
 - Would he/she recommend participating in these meetings to other patients?
 - Does he/she have any recommendations for how participation can be made a better experience?
- Update patients on topics discussed.

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Additional Resources:

- Institute for Patient- and Family-Centered Care. Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit. Tips for group leaders and facilitators on involving patients and families on Committees and task forces, 11-12. Bethesda, MD: Author. Available from <http://www.ipfc.org/tools/downloads.html>
- Grievance Toolkit/QAPI pp 30-35: <http://esrdnetworks.org/resources/toolkits/patient-toolkits/dialysis-patient-grievance-toolkit-1>
- This resource was adapted from ESRD Network 14's *Nothing About Me Without Me*: <http://www.esrdnetwork.org/sites/default/files/content/uploads/PE-in-QAPI-for-Facilities-slides-2015.pdf> and ESRD Network 16's *Tips for Including Patients in QAPI & Governing Body Meetings*: <https://s3-us-west-2.amazonaws.com/nwrenalnetworkorg/net16/QI/LAN/2014/QAPITips.pdf>