

# 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>