PATIENTS & FAMILIES AS ADVISORS IN PRIMARY CARE: BROADENING OUR VISION

There are countless ways that patients with chronic conditions and families can serve as advisors to health care providers, program planners, and administrators. Some are formal and ongoing, others are time limited and informal. All are necessary to ensure that the system of care is centered on patient and family needs, strengths, priorities, goals, and values. Below is a list of some of the ways that patients and families can serve as advisors in ambulatory care.

Patients and families can participate as advisors for:

**Councils, Task Forces, and Work Groups:**
- Create an advisory council of patients and families who receive care at the ambulatory practice.
- Appoint patients and families to task forces and work groups related to facility design, waiting room activities, registration procedures, clinic flow, documentation systems, patient safety, and other quality improvement endeavors.
- Include patients and families on site visit teams to other programs.

**Clinic Programs and Services:**
- Hold brainstorming sessions with patients and families before developing educational materials and involve them throughout the development process.
- Ask patients and families to assist in adapting patient information materials to meet the literacy and language needs of patients served by the practice.
- Include patients and families on teams to plan, conduct, and evaluate group visits.
- Offer opportunities for patients and families to lead or co-lead educational and support programs.
- Create volunteer or staff positions for patients and families such as clinic greeter, peer mentor/coach, or peer liaison.
- Solicit patient and family involvement in building relationships with community programs and resources.
- Ask patients and families to join staff when they meet with funders and community groups.
**Physician and Staff Education:**
- Invite patients or families to present at staff orientation and inservice programs.
- Ask patients or families to offer a professional-in-training the opportunity to spend a day with them to observe how patients manage their care in their daily life.

**Evaluation of Clinic or Program:**
- Conduct follow-up phone calls with patients and/or families after clinic visits to gather their perspectives on how they experience care.
- Hold quarterly or semi-annual coffee hours with patients, families, and staff to explore ideas for improving care.
- Invite patients and families to assist in creating or revising a patient/family satisfaction survey and involve them in developing strategies to respond to concerns and problems reported.
- Convene focus groups of patients and families as specific issues arise. Ask a patient or family advisor to co-facilitate the group.


For additional information about patients and families serving as advisors and leaders in improvement in primary health care, visit the following websites:

- [Center for Medical Home Improvement](http://www.medicalhomeimprovement.org).
- [Institute for Patient- and Family-Centered Care: Advancing the Practice: Patients as Advisors and Leaders](http://www.ipfcc.org/advance/pafam.html).
- [New Health Partnerships](http://www.newhealthpartnerships.org).
2008: Council Established

- Built important and respectful relationships with key leaders in PHMG and with each other
- Reached out to the community at large to bring their voices to the table - Questions That Matter, a series of questions that ask for patient/family perspective about important health issues/concerns and delivery of services. Ongoing part of monthly meetings
- Completed a major DVD project on Patient Safety, which has been used as a model of the impact of advisors across the nation and in Europe.
- Provided a panel of patients who shared their stories at the 2008!ADVANCE! Generating keen interest and interaction with the clinicians of PHMG. Attend !ADVANCE! yearly
- Participated in the AHRQ Medication Management at Home grant as consultants on the study design, conclusions and suggestions about interventions to improve partnership 2007-2010
- Shown a willingness to learn, be curious and be GREAT partners in healthcare policy, services and approaches

2009

- Provided input about RiverBend Pavilion (clinic) wayfinding, amenities, patient care department by department, and communications to patients regarding the move
- Provided input to Ethicist about the regional process of ethical discernment- as a result of his experience a patient advisor has been added to the system Ethicist Committee that meets quarterly
- Advisors have participated in the Regional Network of Care on the steering committee as well as on the Breast Cancer Navigation Team Redesign
- Provided feedback to the University District Hospital Renewal about health information being available to patient/families in common areas
- Created ways to recruit advisors with advisors and was successful in adding diversity of gender and ethnicity
- Provided feedback to the upgrade of www.peacehealth.org, Welcome Packet and Media Materials
- Advisors are invited and attend quarterly All Provider Meetings
- Advisors serve on the Quality Committee for PHMG and liaison back to the PFAC on issues

2010

- PFAC Chairs collaborated with hospital advisor at NICU to make recommendations in 2010 to the PeaceHealth Executive Team of Oregon Region on how to increase the use of advisors in helping improve the experience of care.
- Established an annual Patient- and Family-Centered Award to recognize and highlight examples of great Patient –and Family-Centered Care practice at PHMG
- Promotes visibility of PFAC and partnership with staff through random site visits to thank staff and to make presentations during staff meetings, OPS meetings, etc.
- Advisors providing feedback about wayfinding and artwork selection for UD-PHMG remodel/move
- Advisors connecting with Surgery Institute and wayfinding at the RiverBend hospital facility
- Provided feedback on Patient Connection (now MyPeaceHealth) project
- Input on the CHF Communication Toolkit, Revaccination Project, and redesigned the Consent to Treat form
- Patients and Families Partnership shared at New Nurse orientations
- Participates in Employee Partnership appreciation Days
- Provided feedback on Sports/Camp Physical letter
2011
- Provided input on the Patient Satisfaction Survey
- Provided feedback on new Welcome Brochures
- Partnered with Diabetes Outreach Program with CHI – experience of care and patient communication; helped with designing tools
- Partnered with Service For Excellence: Front Office Experience, including course content
- Patient Advisors served on the Pain Management Committee – New Pain Management Contract developed
- Patient Advisors served on the Dismissed Patient Process Review Committee – new policy implemented
- Provided feedback on the “No News is NOT Good News” campaign with chief patient safety officer

2012
- Patient Advisor participated in the filming of the patient experience in the All-in-One Visit and added content to the film
- Advisors served on the system-wide project for improving the Patient Discharge Summary
- Advisors partnered with the Lane Community College new nurse education program on chronic disease issues and patient experience
- Provided feedback on the Phone Tree Directions menu for the Neurology project
- PFAC’s Service for Excellence Plan – Agenda Setting Notepad and Pen. Piloted with new Medical Home in Adult and Family Medicine

2013
- Program Coordinator serves as a liaison to the Clinical Council and all other Patient Advisory Councils
- Advisors helping patients connect to Patient Connection (MyPeaceHealth)
- Provided feedback to system leaders on future uses of Patient Connection (MyPeaceHealth)
- Provided feedback on system-wide policy on “Termination of Patient Relationship”
- Advisors serve on the Patient Access Committee which includes design of new patient call center
- Established ‘Patient Partners’ in clinics – different level of advisors
- Patient information at the front desk and privacy issues
- Welcome Poster

2014
- Primary Care Medical Home Transformation - ongoing
- Participated in a dress rehearsal for “Shared Appointment” visits done by Dr. Bigley at South Clinic. Gave patient perspectives on the process and concept
- CG CAHPS Survey Results – Focused on 5 key measures (Clinician Group Consumer Assessment of Healthcare Providers and Systems)
- Pediatric Walk-about project – Patient experience
- POS – Collections at Front Desk Service Recovery Feedback. Changed system process.
- MyPeaceHealth - acronym use in general and acronym use within the lab results
- Two Advisors serving on the Oregon Cardiology Redesign project to use a lean approach to clinical workflow within the OC Clinics and the Rapid Access Clinic to improve patient access, throughput and timely results reporting
- CGHAPS Surveys and personal comments
- CCO Report (Accountable Care Organizations)

2015
- Partnering in the system-wide Patient Information Guide redesign
- Collaborated with IT, Legal, Marketing, and Providers on EMR letter revisions
- Piloting revised agenda setting tool
- Clinical integrity and Patient’s Choice
### Ways to Make a Difference

**Patient and Family Advisors** worked on the following activities. The categories represent the amount of effort and time required to complete the work.

<table>
<thead>
<tr>
<th>Easy</th>
<th>Moderate</th>
<th>Difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing input on wayfinding to practices, offices, exam rooms</td>
<td>Mentoring other advisors and recruiting for diversity within council</td>
<td>Participated in content and filming of a new patient experience model of care</td>
</tr>
<tr>
<td>Review of health information and media materials</td>
<td>Participating in organizational learning opportunities</td>
<td>Designed and Produced DVD on patient safety that was used as a model of the impact of advisors</td>
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<tr>
<td>Artwork selection for lobbies and waiting rooms</td>
<td>Establishing PAC award to providers/departments who embrace PFCC Principles</td>
<td>Patient Centered Medical Home transformation</td>
</tr>
<tr>
<td>Providing feedback on Patient Portals</td>
<td>Participating on New Nurse Panels on chronic illness from a patient's point of view</td>
<td>Service for Excellence Plan - Agenda Setting - piloted with new Medical Home In Adult and Family Medicine</td>
</tr>
<tr>
<td>Participating in Employee and Provider Appreciation Days</td>
<td>Sharing personal stories on experience of care</td>
<td>Collaborated in designing course content for front office staff training</td>
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<tr>
<td>Feedback on surveys</td>
<td>Serving on organizational committees - Clinical Councils, Quality Councils, Patient Safety Councils</td>
<td>Participate in interview panels for new Adult and Family Medicine Chief (key physician leader)</td>
</tr>
<tr>
<td>Promote visibility of PAC partnerships by random site visits to thank staff</td>
<td>Collaborated on Welcome Brochures</td>
<td>Help mentor and orient new physicians and managers to the practice</td>
</tr>
<tr>
<td>Ways to Make a Difference</td>
<td>PeaceHealth Medical Group</td>
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<td>---------------------------</td>
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<tr>
<td>Advisor Walk-Abouts - different practices - Report out on patients’ impressions and experience</td>
<td>Partnered with Diabetes Outreach Program on experience of care and patient communication</td>
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<tr>
<td>Redesigned Medication &quot;Opioid&quot; Contract using Language of Caring Principles</td>
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# PARTNERING WITH PATIENTS AND FAMILIES TO ACCELERATE IMPROVEMENT READINESS ASSESSMENT

Name of Organization_____________________________________________________

<table>
<thead>
<tr>
<th>Area</th>
<th>For each item, circle the box that best describes your team’s perspective and experience.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data transparency</strong></td>
<td>Our team is uncomfortable with the possibility of sharing performance data with patient and family members.</td>
</tr>
<tr>
<td><strong>Flexibility around aims and specific changes of improvement project</strong></td>
<td>We have limited ability to refine the project’s aims or planned changes.</td>
</tr>
<tr>
<td><strong>Underlying fears and concerns</strong></td>
<td>We have identified several concerns about involving patient and families on improvement teams and would need assistance in creating a plan for addressing them.</td>
</tr>
<tr>
<td><strong>Perceived value and purpose of patient and family involvement</strong></td>
<td>There is no clear agreement that patient and family involvement on improvement teams is necessary to achieve our current improvement aim.</td>
</tr>
<tr>
<td>Senior leadership support for patient and family involvement</td>
<td>Senior leaders do not consider patient and family involvement in improvement a top priority.</td>
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<td>-------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Experience with patient and family involvement</td>
<td>Beyond patient satisfaction surveys or focus groups our organization does not have a formal method for patient and family feedback.</td>
</tr>
<tr>
<td>Collaboration and teamwork</td>
<td>Staff in this organization occasionally work in multidisciplinary teams to provide care.</td>
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</table>

1. What supports moving in the direction of involving patients and families?
2. What are your current challenges?
3. How confident are you on successfully involving patients and families on your team (on a 1-10 scale with 1 = not confident at all and 10 = extremely confident)? ___________

© 2007 Adapted from a tool developed in collaboration between the Cincinnati Children’s Hospital Medical Center and the Institute for Healthcare Improvement for Web & ACTION: Partnering with Patients and Families to Accelerate Improvement.
HOW TO CONDUCT A “WALK-ABOUT” IN PRIMARY CARE FROM THE PATIENT AND FAMILY PERSPECTIVE

One way to begin working with patients and families in planning for improvement is to explore your primary care setting through the eyes of patients and their families. A “walk-about” is an activity that can be used to obtain patient and family perspectives. If you have patients and families who are advisors within your program, ask them to participate in the activity. If you don’t currently have any patient or families identified as advisors, invite several patients and families who receive care in your facility. Typically it requires two or three invitations to secure the participation of one patient or family member. It is helpful to have two or three patient and family perspectives for this “walk-about”. Select patients and families who are willing to share their opinions. Refer to the resource titled Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings — How to Get Started, Part V: Selecting, Preparing and Supporting Patient and Family Advisors in Primary Care and Other Ambulatory Settings for detailed recruitment guidance.

Instructions for Day of “Walk-About”

Select a time when a broad representation of your staff, including patients and families, can tour the facility together. This activity can be completed one two-hour or, ideally, in two different one-hour meetings. Before you start, share with your group the objectives of the site “walk-about” – to capture the observations, flow and interactions of a typical clinical care encounter. If he or she feels comfortable doing so, a patient/family advisor could lead this tour. The tour should begin at the first point of entry into the facility (e.g., the parking lot), and continue through all of the activities of a typical care visit, including a simulated visit and exam. Consider all the experiences of the visit, not just the time a patient spends with a care provider in the exam room. You want to specifically explore how the following elements promote preventive care, healthy behaviors, self-management of chronic conditions, and encourage patients and families to be active members of the health care team:

- How patients and families are prepared for their clinic visit.
- How patients and families are greeted.
- The visual appearance, the processes of care, and exchange of information in the administrative areas (check-in, etc).
- The visual appearance, the processes of care, and exchange of information during a visit and exam.
- Patient forms and educational materials (or anything else they may receive or need to fill out as part of a visit).
- Characteristics of the physical environment (signage, artwork, color, lighting, visible equipment and arrangement of furnishings).
- Public materials (e.g., displays, signage, posters, magazines, announcements).

The team should collect “evidence.” To help you with this task you will want to gather

- Clip board and paper for each note taker(s);
- Large manila envelope to hold all of the patient forms, education materials given to the patient during the simulation;
- If possible, a digital camera or video camera.
Assign one or more of the team to document the “walk-about” through:

- Digital photos or video - that ideally is used by the patient/family member
- Notes from observation of simulated check-in processes, patient visit and exam.
- Patient forms and educational materials.
- Specific quotes or messages on posters, signage or other announcement.

**Tips for Photos/Videotaping**

- Make sure that the photographer (patient, family member, or staff) is specific in the capturing the detail of the particular element of the environment/interaction in the photos or video. What is their perspective?
- At least one person should be assigned to take notes during the tour to capture these thoughts. While this exercise is designed mainly for staff to see the care experience through the eyes of patients and families, all team members should be given the opportunity to identify elements and processes that are important to their work with patients and their families. These may be elements or processes that physicians and staff perceive as helping or hindering their ability to encourage patients and families as active partners in care and decision-making.

The “walk-about” can be beneficial for patient and family members to start building their interest and confidence level for serving as an advisor. It builds their understanding of staff and physician perspectives, care processes, and the environment of care. It allows them to begin to get a broader view of the positive elements of the system of care as well as areas for improvement.

**Instructions for Summarizing Findings From Day of “Walk-About”**

Set aside a meeting time when all members who participated in the “walk-about” can attend, to discuss what the team discovered. Bring all the “evidence” to the meeting: notes, photos taken, forms/materials collected, and discuss what you have learned about the experience of care through the eyes of patients and families.

Discuss selected photographs and tools, using a root-cause model questioning and discussion – examples:

- What do you see here?
- What is really happening here?
- How does this relate to our clinic’s experience of care?
- Why does this concern, situation, practice exist?
- How can we use this information, new understanding, to reinforce current best practices or guide what can we do to improve our practice?

We encourage you to use tool titled, *Wearing New Glasses*, to record the findings of your “walk-about” during this meeting time and plan for change. Record all ideas and suggestions.