

# Patient and Family Engagement

## Why Do It?

Patients are the most important members of a health care team. Engaging patients at the visit, clinic and organizational levels is an essential, but often difficult, task of primary care homes. At the visit level, the focus is engaging patients in understanding the primary care home and their role in their own care. It also includes patient-centered communication such as shared decision-making. At the clinic level, engagement involves effectively partnering with patients and families in clinic improvement projects through patient surveys, episodic partnerships or forming a patient advisory council. Finally, where a larger organization exists, patients can offer invaluable insights for strategic planning and other high-level visioning endeavors. Also see the tip sheets on *Quality Improvement* and *Comprehensive Care* for related suggestions. The Institute website also contains a variety of resources around [Patient and Family Engagement](#), including webinars such as “[Preparing for Collaborative Work with Patient and Family Advisors](#)”.

## Where to Start

**1. Explain what PCPCH is** to your patients along with the type of care they should expect. Patients’ experience of care evolves with the adoption of the PCPCH model, so the shift in patient rights and responsibilities will be more apparent to clinic staff at first. It is important to affirm how valuable their role is and that their PCPCH is there to assist them with their needs. Do so by:

- a. **Solidifying their place on the health care team** through pre-visit or between-visit check-ins via phone, email or patient portals; and
- b. **Paying special attention to patients with additional difficulties navigating the health care system**, including Medicaid patients, patients with complex needs, the elderly, and ESL patients (also see the tip sheet on *Care Coordination*).

*“...When we talk about shared decision-making, that’s a huge change. For a lot of our providers...that is not how it goes. So, to have such a transformation to we are doing what we are supposed to, we pushed them to do that, to we are going to have these conversations with patients...”*

**2. Engage in shared decision-making** with your patients. Shared decision-making is two-fold: it requires flexibility and compromises from the patient and provider as well as a willingness of the care team to modify workflows or processes when they do not work for a specific patient. Also see the tip sheet on *Culture and Change Management*.

- a. **Discuss and build individual health plans on the foundation of the patient’s values.** For example, a patient may care about their ability to play with their children without getting easily tired or sore, rather than simply working toward lower cholesterol or blood pressure.

*PCPCH tip sheets were developed from the reported experiences of recognized PCPCH’s, by a Portland State University research team under contract with the Oregon Health Authority, 2016. These recommendations are not part of the official OHA technical assistance guide and are not a guarantee of program recognition. Access this Tip Sheet and other resources: <http://www.pccpi.org/search/resources>.*

- b. **Engage in active listening** with your patients to become more aware of their goals and understand their health behaviors in the context of their life and family situations.
- c. **Be patient** when developing workflows and protocols. This is an iterative process, but you will find a shared decision-making tool that works best for both clinic staff and patients. For instance, adding a question on the likelihood of following through with an invasive screening procedure can facilitate conversations about a patient’s other options while simultaneously improving screening rates (see the tip sheet on *Comprehensive Care*).

**3. Effectively Partner with Patients and Families in Clinic Improvement Projects.** Patient feedback is an integral part of patient-centeredness. It provides indispensable advice which can ultimately make a clinic run more smoothly.

Patient feedback may be obtained in the following ways:

- a. **Provide surveys** to patients; this will be required for PCPCH recognition in 2017 (see the tip sheet on *Collecting and Using Data*).
- b. **Establish Patient and Family Advisory Councils (PFACs)** where members can explain grievances, offer suggestions and brainstorm or modify new workflow processes.
- c. **Invite patients into your clinic’s quality improvement meetings** and receive feedback from the beginning.

*“This is why we are doing these things, because we need to get this perspective here. I know behavioral health is really hard, but look at your CAHPS survey, your entire population says you don’t do well at this, let’s focus on it...”*

### Tips for Making the Most of Patient and Family Engagement

- ❖ Since many patients have not felt they are central to their own health care decision-making for a long time, some of them may not be ready to become a member of the own team – which is okay! **Encourage these patients to ask questions** during or between visits and **offer them educational materials on PCPCH**, such as brochures, letters, or via agreement forms that inform them of their clinic’s status as a recognized PCPCH.
- ❖ Just like patients, providers who have not modeled patient-centered care may not be ready to engage patients and their families. **Allow them to discuss their reservations** and **offer these providers evidence of the benefits of patient and family engagement**. Remind them that it will become easier over time (see the tip sheet on *Leadership*).
- ❖ As with any other process, **it is important that your PFAC works for your clinic and patients**. PFACs can meet monthly, quarterly, or as one-time focus groups when rolling out a new workflow process -- whatever meets your needs (see the tip sheet on *Quality Improvement*).
- ❖ **A PFAC should be representative of the clinic population to ensure all voices are heard** and are not comprised wholly of one certain population group. If the group gets “hijacked” by a specific member or two, have a separate meeting with those members and allow them to voice their concerns freely. This will enable the council to get back on track.

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