Engaging the Patient
Perspective Produces
Real Change
“This was a great learning experience—seeing another side of health care. Feeling like I was contributing was great.”
-- Patient Partner

Patient Partner Project 2.0

**Background:** Patient Partners were introduced as members of ambulatory quality improvement teams in January 2011 as part of the Primary Care Renewal project. Patients attended collaborative meetings with their practices to offer insights on the patient experience of care. A framework was developed by Jessica Osborne-Stafsnes and Betsy Stapleton to support both practices and patients in developing meaningful working relationships. This included:

- The development of a patient recruitment process
- Assistance for practices to address trouble-shooting challenges
- Patient orientation to the collaborative, key concepts, and strategies for working in multi-stakeholder groups
- On-going specialized patient support (patient-only meetings, resource binders, and special learning opportunities)
- Integration of the patient viewpoint in all collaborative meetings

**Successes:**

- Retained 15/18 original patient partners throughout the PCR year. All but 1 PCR practice met the “Patient Partner Requirement” (have a patient partner present at 50% of all collaborative meetings).
- Patients worked collaboratively with their team to design their practice brochure. All of the brochures were assessed by the collective group of patient partners for “patient-friendliness”
- Subtle encouragement via PCR Collaborative meeting evaluations increased the number of practices engaging patients in their team meetings (not a requirement of participation).
- Several practices made great strides in engaging their patients in innovative ways
- Patient Partner attendance at collaborative meetings was better than provider attendance.
- The “Patient Presentation” component of each collaborative meeting was consistently evaluated with the highest score for the didactic parts of the collaborative meeting (see handout).
- Success of early work with Patient Partners has lead to spin off projects and invitations to speak about our work both regionally and nationally
Challenges:

- Medical practice teams who were “low engagers” in the PCR collaborative also struggled to engage their patient partners effectively.
- Several practices and patients were mismatched in their interest and engagement levels.
- After the “patient brochure” project ended, many practices struggled to work with their patient partners in other projects.
- Transportation to and from meetings was a barrier for several patients involved.
- In a post PCR survey, many practices reported that they had made “very few” changes in clinical workflow, clinic environment, or care delivery as a result of working with their patient partner.
- Measuring the impact of patient engagement in quality improvement work has proven to be a challenge.

Next Steps:

PCR 3.0 features a heightened focus on patient experience of care. Teams have been asked to recruit two patient partners to participate on their quality improvement team and patient participation in team meetings is now a requirement of the collaborative.

Additional efforts include:

- Rapid-cycle patient experience surveying on PCR 3.0 topics conducted in-office by trained patient partners.
- Patient engagement practice coaching to model effective strategies for patient engagement in team meetings.
- Work to develop metrics to better evaluate the impact of this work.

“This is the best idea!” – PCR team referring to the engagement of a patient in their collaborative team.
Report on Patient Engagement Activities in Maine’s Twenty-Six Patient Centered Medical Home Pilot Sites

October 2011

Drafted by the Patient Family Leadership Team:

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Report on Patient Engagement Activities in Maine’s Twenty-Six Patient Centered Medical Home Pilot Sites

Executive Summary

Maine’s twenty-six Patient Centered Medical Home (PCMH) pilot sites have been working for nearly two years on a set of core expectations (see Appendix D) meant to transform their practice. One of those core expectations is to engage patients and families in care transformation by including patients in leadership and developing ways to get consistent feedback from patients.

The Patient Family Leadership Team (PFLT) began to support the practices in their patient engagement work in mid 2010. At the beginning of 2011, this group began to develop a survey to capture the successes and challenges that practices were encountering in getting patients more involved.

The survey was conducted April-August of 2011; as a result of this work we now know that:

- 14 PCMH pilot practices (54% of sites) have on-going advisory groups
- 3 PCMH pilot practices (11.5% of sites) advisory groups that have met at least once
- 6 PCMH pilot practices (23% of sites) plan to meet by the end of this year
- 3 PCMH pilot practices (11.5% of sites) requested planning support to get a group going

In addition, the surveys revealed many promising strategies for getting patient feedback and using that feedback to improve the practice. These are discussed in more detail in this report.
**Background**

The Patient Family Leadership Team (PFLT) was created by the Maine Patient Centered Medical Home (PCMH) pilot. The group, which consists of individual consumers, consumer advocates and quality improvement professionals, provides input on the development, implementation and evaluation of the PCMH pilot to make sure that it meets the needs of participating patients & families.

The PFLT is currently funded by an Aligning Forces for Quality (AF4Q) grant. Through this grant, the PFLT is able to 1) offer patient and family engagement support and technical assistance to the 26 PCMH pilot practices, and 2) engage, and support patients, along with their families and care givers, in having a voice and leadership role in the design and delivery of patient-centered care for themselves and their community.

During the spring and summer of 2011, the PFLT conducted interviews with staff at all twenty six PCMH pilot sites (see Appendix B for list of practices.) This interview was created to get a sense of the practices’ progress in implementing patient engagement. This was the first large-scale interaction between the PFLT and the PMCH practices and its success was made possible by the cooperation and support of practice staff. In fact, the PFLT was able to connect with at least one staff member at every single pilot site to gain perspective about their patient engagement work. Interview questions are included in Appendix A. At the end of the pilot, the practices will be measured on their progress for Core Expectation #7, which is considered a “must pass” element in 2011:

**7A**  
With assistance from PCMH Pilot staff and consultants, practice has identified at least two patients or family members to be part of the practice leadership team.

**7B**  
Practice is using one or more mechanisms for routinely soliciting input from patients and families on how well the practice is meeting their needs.

The interviews were designed to seek feedback from the practices in the successes and challenges they have had in moving toward “fully implemented” in both 7A and 7B. Fully implemented is described as:

**7A.** Patients and family members are a regular part of leadership meetings or some advisory process to identify needs and implement creative solutions. Tangible supports are in place to enable patients and families to participate in this process (e.g., after hours events, transportation, stipends, etc.)

**7B.** Practice systematically learns about patients and draws upon patient and family input to design and implement office changes that address needs and gaps in care.
The charge of the PFLT is to support practices in setting up patient engagement frameworks in their practices; we designed the survey to get feedback from all practices about what they were doing, how they were doing it, and what kind of support they might need in the future. From on-site consultations and other feedback that practices had been providing, it was clear that there was a wide range of progress and many strategies that sites were using to move toward better patient engagement. This document seeks to highlight those strategies, to celebrate successes, to point out challenges, and to make recommendations for the next phase of patient engagement at the twenty-six pilot sites. It is also intended to be a resource for the practices to encourage shared learning and ongoing peer to peer exchange.

Summary

For the majority of practices, integrating patients into practice leadership (Element 7A) has been done through the creation of Patient Advisory Groups.

Fig. 1: Progress in Establishing a Patient Advisory Group

As this chart shows, over half of the PCMH pilot sites (14 sites total) indicated that they have an ongoing advisory group in their practice. Another three sites have an advisory group that has met at least once; and six sites indicated that they are planning to develop an advisory group within the year. Only 3 of the sites have not yet convened an advisory group, although two of these practices are exploring the possibility of such a group.

For those who have begun this work, there is no perfect model. The sites have learned that the development of an Advisory group (alternatively called –Patient Advisory Group,” –Patient Family Advisory Group,” –Practice Advisory Team,” or –Patient Advisory Board”), is an evolving process, dependent on leadership and staff support, patient availability, practice readiness, and practice resources. The process also depends on where the practices are in terms of meeting the nine other PMCH core expectations. In other words, flexibility in exploring how patient engagement works in a given practice is vital. As such, the groups vary in how they have dealt with issues of: a) formal structure, b) meeting frequency and c) time of day. Some groups are more patient directed while others are more driven by providers, in terms of overall coordination.
Fig. 2: Feedback Loops in PCMH Practices

Getting Feedback from Patients-How are Practices Doing It?

<table>
<thead>
<tr>
<th>Recruitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider asked patients to be on Advisory Board</td>
</tr>
<tr>
<td>Other staff asked patients to be on Advisory Board</td>
</tr>
<tr>
<td>Advertised in newspaper</td>
</tr>
<tr>
<td>Letters of invitation sent to selected patients</td>
</tr>
<tr>
<td>Created a brochure for recruitment</td>
</tr>
<tr>
<td>Posted a call for members on practice bulletin board</td>
</tr>
<tr>
<td>Collaborated with other practice and hospital patient advisory efforts</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advisory Board/Group Structure and Process</th>
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</thead>
<tbody>
<tr>
<td>Used charter to develop group roles, terms of service, and direction for the group</td>
</tr>
<tr>
<td>Average 4-6 patients per group</td>
</tr>
<tr>
<td>Offered stipends, gas cards, child care, and other supports to ensure participation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feedback Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surveys-Avatar, Press-Ganey, homegrown tool, CAHPS, targeted Picker survey (i.e., 40 patients per month)</td>
</tr>
<tr>
<td>Question of the month</td>
</tr>
<tr>
<td>Invite patients to be part of monthly practice leadership team meeting</td>
</tr>
<tr>
<td>Convene patient focus groups before BOD meetings</td>
</tr>
<tr>
<td>Put up Bulletin Board with space for suggestions and tracking what practice does with feedback</td>
</tr>
<tr>
<td>Practice manager makes personal contact with several patients a day</td>
</tr>
</tbody>
</table>

The importance of meeting the practices where they are is reflected in many of the comments from staff interviewed at pilot sites:

“*It’s important to start small and build.*”

“*It’s harder than it sounds to get the right combination of people; be prepared to take a long time.*”

“*[The staff] knows that the patient advisory group wants to see its work go somewhere [and so] we have to connect it to other avenues in the practice where patients can have influence.*”

“*[Our practice feels that] standardization of patient engagement may not be realistic in all [PCMH pilot] practices as we vary in geographical service area, patient population served, etc. It takes real innovators to be successful.*”
The comments speak to the struggles that many sites shared, in terms of pulling together the right formula for an advisory group within their practice. A few sites noted, for example, that their efforts to start and maintain a patient advisory group had come in fits and starts; one practice found success in its efforts only after two attempts with two different groups of patients. Another practice highlighted that while it has a single dedicated member on its advisory group—who is currently providing feedback to the practice—outreach to other patients has not yet resulted in a group that has gelled.”

At least one practice used a highly structured and patient centered approach to starting their advisory group. This practice reported that starting and sustaining the group is going well because of that approach:

“We have been pretty successful so cannot identify specific challenges.
We have not had to cancel a meeting, as our members honor their commitment period. Turnover is minimal and has been mostly based on health issues. Out patients overall are really engaged and want to see improvement and they are willing to work for it.”

So, despite these and other challenges, it is clear from the interviews that once patients are engaged they can have an impact, almost immediately, on how the practice delivers care:

“Providers now go to patients first when they want to know how to change something that isn’t working.”

“Patients developed a list of things that they wanted to see change and everyone voted on this list. We organized them as “easy” and “challenging” projects and this helped the group get a sense of what we were going to accomplish together.”

“Patients bring such a good perspective that the practice does not see.”

“Patients give you insight into what you cannot see yourself.”

“Patients feel like they have a voice; it’s really important to our patients here that they feel heard and cared for.”

“The patient’s voice must be heard and is very much welcome at [our practice]. This is always in the forefront of discussions within the practice, whether formally or informally. Patients are willing to lend their experience to us.”

For those who have started an advisory group, not a single site reported that this group was impacting the practice in a negative way. The make-up of the groups may have something to do with this, as the formal mingling of patients and staff leads to better communication. In many cases, the groups are an even mix of patients and practice staff. In several instances, the Medical Director acts a champion who makes it clear by attending these meetings that patient engagement is a priority for the practice. As
one practice manager summarizes: ‘I see patient-provider collaboration as a process that will continue to improve communication, decrease costs and improve the overall health of the population.’” A number of practices who overcame their initial struggles with developing a group comment on the surprising rewards of engaging patients. As another practice manager put it, ‘engaging patients is the hardest core expectation but the most fun.’”

As noted previously, the survey respondents also openly shared the challenges to establishing patient engagement in their practices. The chief obstacle for many practices is lack of time, coupled with the many priorities of the PCMH pilot. As one interviewee put it, ‘—this element [patient engagement] is one of ten we have to focus on.’ Some of the specific challenges that practices shared in establishing a patient engagement framework include:

Finding a focus. Two of the twenty six interviewees shared this as a specific barrier, although echoes of this challenge came up with many of the other responses as well. The challenge seems to be that pilot sites want to engage patients on issues that keep them coming to meetings—and identifying what is going to keep patients coming can be difficult. As one interviewee noted, ‘—some patients have their own agenda and they drop out [when that agenda is not fulfilled].’” Or, as a couple of pilot sites experienced, it has been difficult to ‘—have a new agenda every time and find new items to discuss.” Also, part of the challenge in finding focus has centered on the struggles for both the patients and the practice staff to define their new roles. One respondent explained that the challenge has been ‘—not knowing what the patient’s exact role is;’” another echoed this remark, saying ‘—staff feel they have to change what they talk about.”

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A PROMISING APPROACH FOR FINDING FOCUS

Finding a focus before inviting patients can be a useful strategy, since patients know what they are signing up for; this strategy may be useful for starting a group but practices should also consider the importance of patient feedback in setting the tone, agenda and focus of advisory groups.

Finding enough staff and time. These challenges blend together at many of the pilot sites. Without exception, the patient engagement work at the pilot sites is borne by one or more staff who have multiple other responsibilities; in the case where a site hired a dedicated staff person to coordinate the advisory group, even that person needs the support of the practice manager and other staff to meet patients’ needs. Many of the comments about barriers to patient engagement focused on
the fact that the practice does not have adequate staff or enough time to devote to doing the patient engagement work at the level they want to. This comment summarizes the challenge best: “Time and resource challenges are significant. Our practice manager oversees multiple sites located in different towns and it can be difficult to get providers to allocate adequate time to [patient engagement work].” Also, the bulk of the advisory groups (11 of 14) that are formed meet in the evening, requiring staff to put in additional hours that are not reimbursable to the practice, at least not in terms of dollars and cents.

A PROMISING APPROACH FOR FINDING STAFF AND TIME

Practices can consider banding together to improve patient engagement activities, which could provide easy access to tools for collaboration and activities, as well as contacts to practices far along in patient engagement work.

Keeping steady patient groups. The lack of a steady group of patients happens in many practices because of the challenges that patients face in their daily lives, as well as they challenges that practices face in managing day to day operations with limited time and resources. Many of the practices are beginning to put supports in place to help encourage patients who might be struggling, such as stipends, gas cards, child care or transportation. However, most practices will have to deal with changes in the patient participation regardless of those supports. Groups that have had less of an issue with keeping patients report that they set up a term of service (1-2 years) and developed a charter document (see Appendix F for a template) spelling out the commitment that a patient makes when becoming part of the group. These may help struggling practices find the right core group of patients who can stick it out for the long term. One interviewee also noted that to keep patients together, the practice needs a facilitator who can support and manage the groups and also “look for solutions” when an issue comes up.

A PROMISING APPROACH FOR KEEPING STEADY PATIENT GROUPS

In order to keep the group going, a strong facilitator is key. Practices should be looking for
staff and patients that can manage a group and look for solutions when issues come up.

More Promising Practices in Patient Engagement

The following summary of interview responses illustrates the many ways that the PCMH sites are moving toward developing –one or more mechanisms for routinely soliciting input from patients and families on how well the practice is meeting their needs” (Element 7B). Along with the advisory groups most of the practices also are seeking more ways to bring the patient voice into their practice, whether by survey, focus group, or one to one discussion with individual patients. Figure 3 illustrates some specific ways that practices are building their capacity to get routine input from patients

Fig.3: Promising Practices in Patient Engagement

<table>
<thead>
<tr>
<th>What have practices used the feedback for?</th>
<th>How are patients supported to attend meetings or otherwise provide feedback?</th>
<th>What resources are practices using to foster patient engagement?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Future planning for service expansion</td>
<td>Patients provided with an orientation</td>
<td>Regional group (central ME) organized to share patient engagement best practices</td>
</tr>
<tr>
<td>Wait time study and improvement project</td>
<td>Practice created an orientation packet</td>
<td>Patient Family Leadership Team has come to meetings, done phone calls, met with practice staff</td>
</tr>
<tr>
<td>Waiting room improvements (i.e., walk through project to make practice space more patient centered)</td>
<td>Provide stipends and/or mileage for meetings</td>
<td>Various materials from the Institute for Patient and Family Centered Care (IPFCC)</td>
</tr>
<tr>
<td>Revamping phone system</td>
<td>Provide food at evening meetings</td>
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<tr>
<td>Bring patient feedback to weekly provider huddles</td>
<td>Provide care for kids if parents cannot otherwise make the meetings</td>
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<tr>
<td>Monthly practice newsletters</td>
<td>Practice has dedicated staff who is main contact for Advisory group members</td>
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<tr>
<td>Changes to referral process</td>
<td>Patients get reminder calls before meetings</td>
<td></td>
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<tr>
<td>Changes to appointment process, incl. developing open access schedule</td>
<td>Practice provides reimbursement for out of pocket expenses</td>
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<tr>
<td>New patient packet</td>
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<tr>
<td>Developing patient portal</td>
<td></td>
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<tr>
<td>Signage/wayfinding</td>
<td></td>
<td></td>
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<tr>
<td>Improvements to care management program (i.e., more community linkages, help with insurance issues)</td>
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</table>
Recommendations for Bolstering Patient Engagement Activities in PCMH Pilot Sites

The successes of the practices are many, and yet even those far along in the process are looking for ways to share their experience and to learn from others. The Pilot learning sessions offer some of that networking, but many of the practices asked for more. This desire for more formal and facilitated discussion about patient engagement is one of the most promising areas for expanding support for the practices.

One finding from the interviews is that many of the practices were not aware of the expertise and support available through the Patient Family Leadership Team, who has shared its menu of services (see Appendix B) with practices through email and onsite presentations. Over the next year, the PFLT has some capacity to help expand the formalized learning for patient/consumer engagement. As such, we recommend the following:

October 2011-January 2012

- Send report to all PCMH practices
- Provide interested PCMH pilot sites with a list of customized recommendations based on interviews;
- Provide interested PCMH pilot sites with list of “Shared Learnings” from the interviews;
- Explore options to develop a website or improve the existing Quality Counts section devoted to PFLT/PCMH;
- Use the Quality Counts website to advertise more regularly services the PFLT provides;
- Create a "Patient Engagement Tip of the Month” for use in communication with PCMH sites;
- Use PFLT members to provide more on site technical assistance to the practices, either at individual sites or with small groups (i.e groups with similar struggles, groups where one practice mentors another practices);
- Revamp the PFLT team to include representation by consumers statewide and supported by a partnership with AAAs and patient engagement specialists;
- Solicit more practices to apply for Innovation grants (see below)*

February 2012-May 2012

- Create frequent opportunities for practices to meet and collaborate with each other regionally—both providers and patients from PCMH sites, esp. within existing Learning Session framework;
- Establish regular "Patient Engagement" check in calls with topics that practices identify;
Develop and conduct interviews of patients on the advisory groups to understand how they see their involvement within the PCMH practice and patient engagement activities statewide—share best practices from the patients’ perspective.

June 2012-December 2012
- Work more closely with practice patient advisory groups, including recruiting individuals for PFLT;
- Facilitate development of regional collaborations supported by PFLT and AAAs;
- Establish the PFLT as the Statewide clearinghouse for consumer/patient engagement in quality improvement, PMCH, and practice transformation;
- Develop and conduct follow up interviews with practices.

*The PFLT has given an “Innovation Fund” grant to about half of the PCMH pilot sites. The practices are using the grants to develop videos, pay for stipends and/or mileage for participating in an advisory group, or to develop materials. The successes of these projects should be monitored and any outputs—such as patient videos—should be featured at a future learning session and perhaps added to the list of promising practices.”

APPENDIX A

**Consumer Engagement Check-In Questions for PCMH Pilot Practices**

**Part One: Patient Advisory Groups**

1) Where is your practice, at present, in terms of engaging a patient advisory group? (Use the list to prompt them if they don’t provide the answer. Record their answer using the list)

- Started and held at least one meeting
- Forming and planning to hold a meeting in a month or two
- Considering yet not ready to schedule a meeting
- On the list of ‘TO DOs’ yet not there yet

2) What is the make-up of your patient advisory group? (i.e. number of patients and practice staff by professional type)

3) Did you provide an orientation for your patients? If so, please provide a brief description of the orientation.

4) What resources have you used to help advise, model, or organize your Patient Advisory Group effort?

5) If you have not used any, are you aware of and/or planning to use any?

6) What topics have been most and least engaging?

7) What challenges have you encountered to establishing and/or maintaining a patient advisory group?

**Part Two: Surveys, Tools, Resources and Benefits of Patient Engagement**

8) What patient survey and/or experience of care evaluation tools are you using or considering using?

9) In addition to patient surveys and a patient advisory group what other ways have you sought to engage patients and get the patients perspective of your practice?

10) Have you used information gained from the surveys, Patient Advisory Groups and other patient engagement activities? If so, how has this information benefited your practice and/or the patients you serve?

11) Please comment on any other benefits, you see to your practice, of engaging patients in the PCMH transformation effort?

12) How can we better share best practices and consumer engagement tools across the PCMH pilot practices?

13) Are you aware that the Patient Family Leadership Team is a resource for your practice in assisting you with patient engagement issues and that you can learn more about us on the quality counts website?

14) What do you want to tell us about patient engagement that we haven’t asked?

**APPENDIX B**

**2011 Technical Assistance-Menu of Services Available to PCMH Pilot Practices**

**One on One Support**

Face to face meetings- 1 hr session with members of the Pt Family Leadership Team

TA Phone calls on issues important to your practice-30 min session on topics or issues related to patient engagement in your practice
Presentations to staff, patients, community members on pt engagement issues
Facilitation of kick off pt advisory meetings as requested

**Regional Gatherings**
Facilitation of regional PCMH pilot site meetings to discuss pt engagement strategies

**Team Calls**
Tip of the Month related to Pt Engagement-delivered during already scheduled team calls

**Communications**
Tip of the month available to plug into practice newsletters or other communication with patients and families

**Webinars**
Institute for Patient and Family Centered Care offerings on various topics related to pt and family engagement (4 webinars available to Maine)
Institute for Patient and Family Centered Care tailored offerings based on feedback from PCMH pilot practices (2 webinars available to Maine)

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621-0677, x 216
dshargo@mepca.org

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**APPENDIX C**

<table>
<thead>
<tr>
<th><strong>PCMH Pilot Practice (26) List</strong></th>
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<tbody>
<tr>
<td><strong>FAMILY PRACTICES</strong></td>
</tr>
<tr>
<td>Belgrade Regional Health Center – Belgrade</td>
</tr>
<tr>
<td>Blue Hill Family Medicine - Blue Hill</td>
</tr>
</tbody>
</table>
Central Maine Family Practice - Topsham
Community Health Center - Southwest Harbor
Court Street Family Practice - Auburn
Dexter Family Practice - Dexter
DFD Russell Medical Center - Leeds
EMMC Center for Family Medicine - Bangor
EMMC Husson Internal Medicine - Bangor
Four Seasons Family Practice - Fairfield
Lifespan Family Healthcare, LLC - Newcastle
Maine Medical Partners - Westbrook Internal Medicine - Westbrook
Mid-Maine Internal Medicine – No. Vassalboro - Vassalboro
Newport Family Practice - Newport
PCHC Helen Hunt Health Center - Old Town
PCHC Penobscot Community Health Center - Bangor
Seaport Family Practices - Belfast
SMMC Prime Care - Biddeford
Wilson Stream Family Practice - Farmington
MMC Family Medicine Portland - Portland
Swift River Health Care - Rumford
Winthrop Family Practice (MGHA) - Winthrop

PEDIATRIC PRACTICES

EMMC Husson Peds - Bangor
Maine Medical Partners - Westbrook Peds - Westbrook
PCHC Penobscot Peds - Bangor
Winthrop Pediatric and Adolescent Med - Winthrop

APPENDIX D

PCMH Pilot Practice Core Expectations

The 26 participating practices have agreed to implement the PCMH model that includes achievement of the following “Core Expectations” that address key practice changes directed by the nationally recognized Seven Key Principles of the PCMH.
The practices are being supported in their efforts to meet the Core Expectations and transform to a the PCMH model of care through participation in a series of Learning Collaboratives and leadership conference calls, practice coaches, the Community Care Teams, the Patient Family Leadership Team along with training and technical assistance provided by the AF4Q and other state or national quality improvement, consumer engagement and payment reform organizations.

1. Demonstrated Physician leadership for improvement
2. Team based approach
3. Population risk-stratification and management
4. Practice-integrated care management
5. Enhanced access
6. Behavioral-physical health integration
7. Inclusion of patients & families
8. Connection to community/ local Healthy Maine Partnerships
9. Commitment to (new: cost transparency) and waste reduction
10. Integration of health IT
Recognizing the essential role of primary care in our healthcare system, the Maine Quality Forum (MQF), Quality Counts (QC), and the Maine Health Management Coalition (MHMC) have been working together since 2008 to lead the Maine Patient Centered Medical Home (PCMH) Pilot. The ultimate goal of this effort is to sustain and revitalize primary care, both to improve health outcomes and to reduce overall healthcare costs, for all Maine people. Planning and implementation of the Pilot is being directed by a multi-stakeholder PCMH Work Group, and supporting organizations which include the conveners QC, MQF and MHMC, along with the Maine Health Access Foundation, Harvard Pilgrim Health Care, Martin’s Point Health Care, Anthem BCBS, and the Davis Family Foundation. After the initial planning period in 2008 and early 2009, the PCMH Work Group selected 26 primary care practices in May of 2009. This was done as a first step towards achieving state-wide implementation of the PCMH model.

The 26 participating practices include a diverse mix of 22 adult and 4 pediatric practices chosen for their demonstrated leadership and commitment to the principles of the PCMH model, diversity of practice size and location, ownership, and ability to link with and leverage existing improvement opportunities and community partnerships available across the state. After their selection in 2009, the 26 practices completed an initial “ramp-up” period during which they obtained NCQA PPC-PCMH medical home recognition and established new payment agreements with the participating Maine Care, Harvard Pilgrim, Anthem and Aetna health plans. The payment agreements provide an alternative reimbursement model, which includes a per member/per month fee (PMPM) designed to recognize the infrastructure and system investments needed to deliver care in accordance with the PCMH model, and reward practices for demonstrating high quality and efficient care. The original 3-year period of the Pilot began January 1, 2010, with PMPM payments to the pilot
practices starting at that time.

Since then Maine has been chosen to participate in the Medicare Advanced Primary Care Practice (MAPCP) demonstration, which will run for a 3-year period starting January 1st, 2012. The MAPCP will provide additional resources including a PM/PM payment for all Medicare patients attributed to the PCMH practices. To accommodate the MAPCP timeline the PCMH pilot, although still evaluated at the end if the original 3 year time period, will continue to run through December 31, 2015.

**PFLT Mission Statement** (approved by the membership on 4-28-2010)
The Patient Family Leadership Team advocates for inclusion of the patient voice to improve health care systems and advance high quality, patient centered care.

**PFLT Vision** (approved by the membership on 05-19-2010)
Maine has a culture of strong and sustainable partnerships among patients, families, caregivers, communities and health care providers to achieve safe, timely, effective, efficient, equitable, and patient-centered care.

**PFLT Values** (approved by the membership on 05-19-2010)
Mission driven: We believe that universal access, high quality, safe, integrated and affordable health care for all people is the cornerstone for a transformed health care system.

Building partnerships: We believe that power comes from collaboration. Patients, families, caregivers, communities and health care providers work as a team to improve care. Collaborative work requires honesty, integrity, transparency and commitment to a shared vision.

Advocating change: We believe that patients, families, caregivers and communities engaged in partnerships with health care providers advocating for change are critical to transforming and improving health care in Maine.

Developing leaders: We believe that to achieve patient empowerment patients, families and caregivers must have information, training and support necessary for developing the confidence and skills needed to be effective partners with their health care team.

Patient Centered: We believe in implementing the seven core principles of the Patient Centered Medical Home (PCMH) which include:
- Ongoing relationship with a primary care provider of choice
- Primary care provider led team of caregivers
- Whole person orientation that includes a behavioral health component
- Integrated care realized through providing care coordination across the health system
- Quality and safety as hallmarks of care, including patient and family care giver participation in the evaluation and improvement of care
- Enhanced access which includes timeliness and affordability of care
- Payment system reform and transparency which acts to strengthen the primary care system and support efficient, effective health care delivery in Maine.
APPENDIX F

Sample Charter for Patient Advisory Council

I. Purpose
Our practice strives to provide excellent compassionate primary and specialty healthcare service and cooperates with others to promote the well being of the people of Maine. Our mission is to care for patients, families, communities, and one another. We also recognize the patient/family as the most important factors in keeping the patient healthy. Therefore, the purpose of our Patient Advisory Council (PAC) is to advise primary care administration and medical leadership on patient needs and primary care priorities from a patient/family perspective. The intent is to influence primary care strategic planning and improve office processes. The plan of our practice is to institute the concepts and core expectations of the Patient-Centered Medical Home into the primary care setting.

II. Policy
The PAC will promote and guide the development of the Patient-Centered Medical Home model into the delivery of patient care. The PAC strives to promote respectful, effective partnerships among patient/families, professionals, and the community that lead to increased understanding and cooperation between patients/families and professionals and ultimately increase patient/family satisfaction and quality of care.

III. Procedure
A. Function
The primary function of the PAC will be to develop and improve mechanisms for patients/families to provide input to administration, department leadership, primary care clinics, etc., so that services are reflective of the values inherent in the core expectations of the Patient-Centered Medical Home Model. The PAC will actively promote patient/family-centered care across the continuum by developing and promoting partnerships between primary care providers, patient/families, and the community.

B. Mission Statement of the Patient Advisory Council
Our practice strives to provide excellent compassionate primary and specialty healthcare services and cooperates with others to promote the well being for the people of Maine. Our mission is to care for patients, families, communities and one another. Our practice PAC will promote the concepts and core expectation of the Patient-Centered Medical Home, which will guide those responsible for providing primary care services. The PAC seeks to accomplish this by educating staff on patient/family issues and educating patient/families on healthcare issues.
The resulting partnership will ultimately lead to increased patient/family and clinical/office staff satisfaction.

C. **By-Laws**

1. **PAC membership make-up** – The PAC will consist of 14 members: seven of these members will be from our practice’s patients and seven will be from diverse members of our staff, along with the Practice Director. The Director of the Residency will serve ex officio.

2. **Committee Leadership** – The PAC will be chaired by two Co-Chairs – An employee along with a patient representative. The PAC will volunteer and vote as necessary both positions.

3. **Ongoing Committee Membership** – Initial membership will be selected by the Patient Satisfaction Team. Once formed, the PAC may establish membership based on an application process. It will be the goal of the group to attract and maintain a diverse group membership generally representative of our patient population without discrimination.

4. **Decision Making** – Decision will be made as a consensus recommendation. That is, if something needs to come to a vote a majority of 51% of members will agree. When unanimous agreement cannot be achieved, tacit approval will be promoted after all sides have been heard, relevant data gathered, and severe consequences of the decision ruled out. At least 50% of Patients and our staff members must be present.

5. Badges will be issued with the title Patient Advisory Council Member and will be worn whenever a member is at a PAC meeting.

D. **PAC Member Term**

There will be a minimum one-year term served by all PAC members, not to exceed 5 consecutive terms with the exception of the CFM Leadership Team.

E. **PAC Meetings**

Meetings will be held no less than quarterly. Additional meetings may be required as deemed appropriate. The group will not meet in August or December. Regular meetings of PAC will be at least 2 hours in length. A light refreshment will be served prior to the meeting.
F. Attendance

Members who have three consecutive unscheduled absences or a total of five unscheduled absences during a calendar year will be evaluated by our practice leadership team for continuation of their membership status. If assessed as not able to fulfill their committee responsibilities they will be notified and may be relieved of their duties as a committee member. Exceptions can be made by the co-chairs for emergencies, inclement weather, unexpected personal or family illness, etc. A co-chair should be notified of the member’s absence 72 hours in advance of a scheduled meeting or as soon as possible.

In the case of a cancelled meeting, the staff co-chair after consulting with the patient co-chair will contact the Administrative Assistant; the Administrative Assistant will be responsible to notify all the members. The meeting will be held one week from the day that it was cancelled unless otherwise notified.

G. Resignation and Removal

A member of the committee may resign at any time by submitting a written letter to one of the co-chairs. A member may be removed from the committee if the member fails to abide by and adhere to the By-laws and guidelines set forth.

H. Confidentiality Statement

To maintain appropriate and confidential handling of information, PAC members are reminded that, out of respect to individuals and hospital policy, discussing any information deemed personal or confidential will not be done OUTSIDE the PAC role. All HIPAA (Health Insurance Portability and Accountability Act) standards and guidelines that apply to the PAC will be adhered to at all times. A confidentiality statement and HIPAA release will be signed at the beginning of the first meeting for all new and joining members.

I. Meeting Minutes

Minutes will be kept by the Administrative Assistant (or designee) of the PAC and will be distributed in a timely manner to all members. These minutes may be distributed by email/mail if the member gives his/her consent.

J. Agenda

The agenda will be established by the PAC Co-Chairs in consultation with the Leadership Team prior to each meeting. Agenda items may be added by any member with prior notification of the Co-Chairs. Agenda items will be evaluated and prioritized by the Co-Chairs.
K. Subcommittees

Subcommittees may be formed to complete tasks or meet a need. In the event that subcommittees are formed or a member participates in a supportive role, this will be done on a volunteer basis.

L. Patient Member Responsibilities

All patient members are responsible for:

- Attending PAC meetings
- Participating to the fullest extent during each meeting
- Participating, as time and interest allow, in additional committees and task forces
- Embracing the mission and by-laws of the PAC
- Advocating the concepts and core expectations of the Patient-Centered Medical Home model
- Adherence to guidelines and ground rules set forth by the committee

All Our Staff Members are responsible for:

- Attending PAC meetings
- Participating to the fullest extent during each meeting
- Participating, as time and interest allow, in additional committees and task forces
- Embracing the mission and by-laws of the PAC
- Educating and advocating concepts and core expectations of the Patient-Centered Medical Home model to fellow employees and students
- Encourage the use of the PAC as a conduit of communication between patient experiences/needs with planning and activities of CFM in the provision of care.
- Adherence to guidelines and ground rules set forth by the committee
## Consumer Engagement & Patient Centered Care Resource List

### 1. Agency for Healthcare Research and Quality (AHRQ)


The AHRQ —Patient Centered Medical Home (PCMH)” Resource center website includes information on how to improve the quality, safety, efficiency, and effectiveness of health care through consumer engagement in the PCMH model. Suggested documents to review include:

- White Paper: Engaging Patients and Families in the Medical Home
- Strategies to Put Patients at the Center of Primary Care

### 2. Aligning Forces For Quality (AF4Q)


The AF4Q —Consumer Engagement” website provides information and resources on the AF4Q Alliance’s 16 communities, including Maine, which are engaging consumers in healthcare quality improvement nationwide. Suggested documents to review include:

- Defining Consumer Engagement Fact Sheet
- Finding your Voice as a Consumer Leader

### 3. Institute for Healthcare Improvement (IHI)

[http://www.ihi.org/knowledge/Pages/Publications/PartneringwithPatientsandFamilies.aspx](http://www.ihi.org/knowledge/Pages/Publications/PartneringwithPatientsandFamilies.aspx)

The IHI —Partnering with Patients” website provides information on patient and family involvement in healthcare quality improvement, research and consumer engagement. Suggested documents to review include:

- Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future
- Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices
- Patient and Family Centered Care Organizational Self Assessment Tool
- (Video) Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future

### 4. Institute for Patient- and Family-Centered Care (IPFCC)


This IPFCC website provides resources to support and advance the practice of patient- and family-centered care. Please note →All information is reprinted with permission from the Institute for Patient-and Family-Centered Care”. Suggested documents to review include:

- Advancing the Practice of Patient- and Family-Centered Care: How to Get Started
- Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Care Settings: How to Get Started
- Partnering with Patients and Families To Design a Patient- and Family-Centered Health Care System
- Revised Partnering w/Patients & Families to Enhance Safety & Quality: A mini toolkit
5. **Maine Quality Counts (QC)**  
The Quality Counts website offers a calendar of related events, program information and resource documents concerning the PCMH and PFLT along with other quality improvement events and initiatives statewide. To access either program click on —Programs” then —Patient Centered Medical Home” or —Patient Family Leadership Team”.

6. **National Partnership for Women and Children (NPWF)**  
The NPWF website provides excellent tools and resources including the —Campaign on Better Care” for consumer engagement in PCMH pilots and programs nationwide including Maine.
PAG Projects in Maine

Belgrade Regional Health Center

- Patient Advisory Survey – Created by the PAC to help determine focus areas for further work.
- Medication Reconciliation – PAC reviewed the current patient handout from the MER, and made recommendations that were then shared with IT to create a more user-friendly version.
- Pre-appointment thought sheet – Created by the PAC to give patients the option to write down the most important topics for focus at their visit.
- Local Community Health Bulletin – Created by the PAC that lists and describes activities available in the community.
- Door improvements – PAC recommended installing automatic doors for the handicapped population, which led to installation shortly thereafter by the community board.
- Newsletter – PAC members will act as contributors and review the patient perspective surveys included in these newsletters.

Husson Internal Medicine

- Newsletter – PAG contributes to the periodic newsletters distributed by the office.
- Policy Notifications – PAG creates flyers that describe office policies in detail, such as missed appointments, patient discharge, and prescription refills.
- Patient Folder Labels – PAG creates the design for the labels to be placed on new patient folders.
Engaging Patients in Improving Ambulatory Care

Appendix

Other Resources


