



April 2012

Patient Engagement:

*Practical Strategies to Engage Patients
in Integrated Health Care*

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I. INTRODUCTION

In 1980, when restructuring the federal community mental health center program, the Mental Health Systems Act sought consumer input on services and treatment. Thus, it has long been recognized that there is value in having patients' voices, opinions, and beliefs shape effective services for behavioral health. This "voice" is even more important now when there is constant pressure to reduce the cost of care, and at the same time increase the quality of and access to behavioral health. The transition to a system of care that is more responsive to and effective with patient needs must include patients as both decision makers and advisors.

Since 2006, the Maine Health Access Foundation (MeHAF) has supported patient-centered care in the state of Maine through its Integration Initiative that has provided funding for providers to integrate clinical services and for quality improvement organizations, state agencies, a professional society, and others to work at state system level. MeHAF specifically addresses patient-centered care in the context of integrated behavioral health and medical services. As stated on the Maine Health Access Foundation website: "This ten-year, \$10 million commitment focuses on promoting better patient-centered care by improving coordination and seamless care delivery between behavioral health and primary care providers."

Through funding from MeHAF, health care organizations throughout Maine have worked to improve integrated services, specifically primary care, mental health and substance abuse and sometimes specialty care such as dentistry. Patient engagement has been a central and required component of their work. This case study describes various approaches to patient engagement in integrated care settings so other providers can learn from and adopt these strategies. The case describes the work of five diverse organizations: Amistad, Pen Bay Healthcare, Sacopee Valley Health Center, Spring Harbor, and Tri-County Mental Health Services. It also includes the Maine Patient Centered Medical Home (PCMH) Pilot, a coalition of organizations working across the state to implement medical home principles, led by Quality Counts, a statewide quality improvement organization. (For more detail on each of these organizations, see Appendix A.) These organizations represent the diverse types of health care providers in Maine, and their approaches and emphasis on engagement activities differ based on the organization's setting and local priorities.

II. BACKGROUND

Patient engagement is critical to achieving patient-centered care which was listed as one of six domains of health care quality in the Institute Of Medicine's (IOM) 2001 *Crossing the Quality Chasm*.¹ In this report, the IOM defines patient-centered care as, "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." Many health care providers have embraced this definition. However, the challenge is putting this definition into practice.

The word “engagement” refers to including a patient at a new level of decision making and participation in the health care system. Much of the early research on patient engagement has considered how to encourage patients, in particular those with chronic health conditions, to be active participants in their own care. The IOM describes four levels at which patients can be engaged in their care: patient experience, clinical microsystems, organizational, and environmental.

Patient engagement techniques and practices can be established at all four levels. More focus has been given to the development of methods that help facilitate and improve patient engagement at the organizational and environmental levels. To date, they include: 1) committing to patient engagement on an organization-wide basis, 2) training staff members on patient-centered practices to then serve as patient liaisons, and 3) providing support staff to help both patients and medical personnel with changing roles.²

At the organizational level, patient advisory committees can be formed to provide perspectives and opinions on improvements, planning, and policy development to leaders at health care organizations. At the environmental level, patients can inform agencies (from local through federal) on current policies and programs. These are the agencies that, ultimately, develop guidelines and reimbursement strategies to further promote patient engagement.

There are a number of national initiatives and resources that support patient engagement to improve health care outcomes and the health care delivery system overall, and there is recognition that in order to make a medical home more patient-centered, patient engagement must be discussed. Yet, while several tools have been developed such as guidelines for patient and provider communication from The Center for Advancing Health, a non-profit research group focused on patient engagement,³ these tools are not yet widely used and disseminated.

There is also momentum and resources at the federal level to engage patients in health care research by increasing their roles in informing research priorities. The Patient Centered Outcomes Research Institute, funded under the Patient Protection and Affordable Care Act, involves patients in shaping its research process, encouraging them to provide input on the health care outcomes they value. The institute’s objective is to ensure patients have easy-to-understand and reliable information to use when making treatment decisions.

Similar to these national environmental level efforts to engage persons with health care needs, the MeHAF clinical implementation grantees have made concerted efforts to improve patient engagement at each level of patient care – experience, microsystem, organization, and environmental – described by IOM. This case study describes strategies the five funded organizations used at the patient experience and microsystem levels, and then at the organizational and environmental levels. The case study will provide insight for other organizations on how to effectively implement patient engagement strategies, with a particular emphasis on the integrated care setting.

III. PATIENT ENGAGEMENT IN INTEGRATED CARE SETTINGS: PATIENT EXPERIENCE AND CLINICAL MICROSYSTEMS

A. Patient Interest and Engagement with Integrated Health Care Services

At the patient experience and clinical microsystems levels, each of the five organizations worked to improve patients’ openness, understanding, and follow-through with integrated care and with their individual health care. The integrated care provided by these organizations includes co-located counseling

and brief behavioral health interventions to address mental health and chronic disease conditions in the primary care setting and through enhanced referral and improved coordination of behavioral and physical health care. Offering these services in a primary care setting is often new for both patients and providers and requires some education of patients on the availability and benefit of these services.

Engagement with a patient is predicated on the establishment of a trusting relationship between the patient and the organization as well as with its staff. Through this relationship, staff can provide education and encourage interest in the concept of integrated health care. Patients also become active decision makers in the development of their own treatment plan, increasing commitment. At this level a patient meets with a provider and returns for care when follow-up appointments are made. Engagement on the patient experience level attempts to address the ancillary barriers to care that may prohibit a patient from returning to care or services. Practices identified relationship-building from the start of providing care and improved ways to maintain contact with patients between visits as the most successful approaches to engaging the patient.

Strategy 1: Reconstruct “Hello”

Patients are likely to become more engaged in their care if they feel welcomed to the health care office by reception and other staff. A warm welcome sets the tone for all the other services a patient receives. It is the first opportunity to communicate to a patient that he or she will be met by a friendly and understanding face, and that staff will be similarly friendly at follow-up appointments. A positive first experience is especially important for patients with behavioral health conditions, as they may have increased anxiety, as well as have had negative experiences with providers in the past. By evaluating and improving the welcome a patient receives, MeHAF grantees improved patient engagement by ensuring patients are receptive to services.

Strategy 2: Assess reception staff responsibilities and training

As the receptionist is the first face a patient sees upon arrival, it is crucial that the reception staff members provide the patient a good experience. Assessing the responsibilities of reception staff members and their knowledge and ability to work with patients who have mental illness is an important step to providing patient-centered care in an integrated setting. Amistad worked with primary care practices to improve patient engagement, especially for individuals with serious mental illness. In particular, they worked with two primary care practices to map the daily activities and expectations of reception staff members and to educate them on ways to improve their interactions with patients with mental health conditions. This helped the whole organization to view its work with a patient-centered lens. Amistad began its training by acknowledging the responsibilities and expectations of the reception staff members, setting the stage for a dialogue on how to provide responsive, flexible, and patient-centered service to patients with mental health conditions. The training acknowledged the role that reception staff members have as the “face” of the organization. They are the first people to interact with a patient but have the least amount of medical training. For example, they usually are not trained in motivational interviewing as mental health providers are, and need the support and knowledge to improve their ability to work with patients with complex needs. The training outlined the patient experience for someone with mental illness and gave examples of how it could be improved by the greeting, attitude, and accommodation of

reception staff members. This included a discussion of the reasons that patients with mental health conditions may be late to, or have to cancel, their appointments. It emphasized the importance of being flexible to patient needs, and with this example, rescheduling a more convenient time for the patient. Overall, the training gave reception staff members a more in-depth understanding of how they are part of the team delivering patient-centered care.

Strategy 3: Develop a comprehensive “welcome” visit for new patients

Sacopee Valley Health Center created a new approach, referred to as a “welcome” visit, to orient new patients to their practice and services. This visit occurred prior to or in tandem with a patient’s first visit to the practice and was hosted by the patient care manager who introduced the patient to the array of integrated services available. The welcome visit is viewed as a two-way “get to know you” opportunity. As the patient is learning about the concept of integrated care, and the available services and the resources, the care facilitator is learning about the patient through initial health and behavioral health screenings. At the outset, the patient and care facilitator can identify any barriers the patient may have and begin addressing them. The visit lays the groundwork, so that when a provider does make a referral to behavioral health or the care manager, the patient is familiar with staff and the rationale for the referred services. Staff perceives that the “welcome visit” help patients utilize available services.

Strategy 4: Introduce care team members in person with a “warm hand-off”

When a primary care clinician provides an in-person introduction to a behavioral health provider, by bringing the behavioral provider to the exam room and saying something like “This is my colleague Bill, and he would be happy to make an appointment with you to talk to you more about the stress you are experiencing,” a patient is much more likely to return for a follow-up visit with the behavioral health provider. Otherwise, receiving behavioral health care has both stigma and fear for many patients. All five organizations embraced the concept of the “warm hand-off” between the primary care physician and the behavioral health provider as an essential component of patient engagement. They found this to be an extremely important component of being responsive to patient concerns and resistance to receiving a new service. Similarly, the introduction of a care coordinator in a “welcome” visit increases the likelihood that a patient will be receptive to working with the care coordinator if referred to him/her in the future. Both the warm hand-off and the “welcome” visit strategies make referrals to a behavioral health provider more seamless. Patients are receptive to this additional provider when referred by a primary care provider they trust, as well as feel “seen” and understood by the providers.

Strategy 5: Address patient needs between visits

Feelings of well-being and recovery can begin in the office between provider and patient, but often patients need additional support between visits to manage their health. It is important to recognize those needs that arise between visits, and to think about how to better address the patient needs. At Sacopee Valley Health Center, staff felt that between-visit contact with patients was critical for those patients with complex needs. They determined that a care facilitator, care coordinator, or care navigator role can support patients in several ways. Sacopee Valley Health Center staff assumes active management roles by contacting patients between visits to check on their progress meeting health goals developed with their behavioral health or primary care provider. They also call patients who miss appointments and discuss

barriers (i.e., lack of child care, transportation) and potential solutions to support the patient in re-scheduling and being able to make the next appointment.

Strategy 6: Customize in-between contacts

In addressing between-visit patient needs, Sacopec Valley Health Center determined that the best way to be patient-centered was to customize these contacts. Staff did this by working with patients to identify the best method for follow-up and by discussing how often and what type of contact (phone, e-mail, texting, etc.) they would prefer. The patient is then in control, and there is agreement before the patient leaves the office on how they will work with the care facilitator to follow up on their goals. They may decide on checking in once a week or once a month, but it is a mutual decision. Further, they determine what time of day is best and make follow-up appointments accordingly.

Lessons Learned/Tips for Patient Engagement in Care

- Elevate the role of front desk staff by making staff critical “patient engagement” team members. Assess their responsibilities and knowledge of the needs of patients with mental health conditions. Discuss with the front desk staff members how they can support patient-centered care.
- Offer an introductory visit to new patients, so they can understand all of the integrated services available and have an opportunity to discuss their needs.
- Customize agreed-upon check-ins between visits for patients who need more intensive management of their care.
- When possible, use “warm hand-offs” to introduce patients to behavioral health providers.
- Provide support and reminders to patients between visits to engage patients in their care plan.

B. Patient Engagement through Shared Decision Making

Through the pursuit of shared decision making, integrated care providers ask patients to take a more participatory role in prioritizing their health needs and choosing the best treatment approach with their providers. In the words of the *Foundation for Informed Medical Decision Making*: “It’s important for patients to understand that options exist for almost every treatment decision—including the option to do nothing.”²

The introduction of patient engagement in the decision-making process is a large shift for many practices accustomed to the traditional model of delivering services. The shared decision-making approach asks patients to take a participatory role by knowing what their treatment options are and asking questions to identify which treatments would be best. Through the process, the patient’s role shifts from listening and

following instructions to becoming a member of the care team whose participation and opinions are valued and recognized as important in achieving wellness. Within behavioral health, depression is one condition where patients can choose from several treatment options. Among the practices working towards shared decision making, practice administrators and project managers said that using motivational interviewing techniques has worked to engage patients in shared decision making.

Each practice felt that it was furthering the skills of patients and providers to get to the point where shared decision making was successful. However, staff also said that shared decision making was not yet routine. Two organizations, Sacopec Valley Health Center and Spring Harbor, described their journeys toward shared decision making as rooted in the use of motivational interviewing. Motivational interviewing is a collaborative approach to working with patients to motivate them to change behavior. The approach is semi-structured and is tailored to each patient's learning style. Because the approach is collaborative, it positions the patient as a partner in her/his own care. As mentioned by Spring Harbor, behavioral health providers have the advantage over medical providers because they have more often been trained in this technique to deliver care. An integrated team offers an opportunity for primary care providers to learn the benefits and techniques of motivational interviewing when taking care of patients with mental health conditions as well as those with physical health conditions.

Strategy 1: Consider new roles for patients and providers

Staff at practices that have worked to incorporate shared decision making into their care of patients note that education for patient and provider is needed to take on new roles. From the patient perspective, the assumption is that patients always want to be in control, but for some, this is a radical and strange idea when they have become used to deferring to their health providers for all the answers. Therefore, some patients need patience and more education to help them transition to this new role. It may take time, and some patients may, in fact, prefer to default to the traditional relationship where the provider has all the answers. As the Executive Director at Sacopec Valley Health Center noted, *"We have moved along a continuum towards putting the patient in the driver's seat, and encouraging the patient to set his/her own goals is an important step in that."*

Strategy 2: Share information

In this new role, patients can be more active if they have more information shared with them and even take some ownership over their records. Toward this end, Sacopec Valley Health Center and other grantees have increasingly moved toward providing copies of medical records and both medical and behavioral health visit information to patients. All of the practices hope to make this information even more accessible in the future through an electronic patient portal that would allow access to records from a patient's home computer. However, among grantees currently providing integrated care, access through an electronic patient portal is limited.

Tips on Shared Decision Making

- Use the skills and training of behavioral health providers to spread the concept of motivational interviewing to medical providers in the practice.
- Acknowledge that patients and providers need coaching and support to be active in shared decision making and provide training to primary care providers and patients.

IV. PATIENT ENGAGEMENT IN INTEGRATED CARE SETTINGS: ORGANIZATIONAL AND ENVIRONMENTAL LEVELS

A. Patient Engagement at an Advisory Level

Beyond the strategies used at the patient experience and clinical microsystem levels, patients have a real opportunity to provide a fresh and honest perspective on how to improve health care services and policy at the organizational and environmental levels. Through patient advisory groups and a consumer board, organizations worked to include the patient in the decision-making process at a systems and organizational level. Patients traditionally have not had an ongoing and institutionalized role as advisors or decision makers in the operations of health care organizations. There are a few exceptions among behavioral health providers, and within primary care at Community Health Centers. However, the role of patients is certainly not robust or universal. Developing a forum for such a patient voice has been a significant activity for several of the funded organizations, including the PCMH pilot, Amistad, Pen Bay, Sacoee Valley Health Center, Spring Harbor, and Tri-County Mental Health. While best practices are the goal, it is also worth noting the differences in these organizations and their approach, and the flexibility in approach may be important when it comes to pulling together a patient advisory group. At a statewide level, the Patient Centered Medical Home Pilot (PCMH) is working with 26 primary care practices to transform their delivery of care. A component of this work is improving integrated health services. As part of this effort, each of the participating practices is expected to develop a patient advisory group. As the PCMH pilot hopes to spread the concept of patient advisory groups throughout the state, and to support practices in developing advisory groups, a Patient Family Leadership Team (PFLT) was convened in 2009 as the consumer engagement advisory arm of the PCMH pilot and funded by a Robert Woods Johnson Foundations AF4Q consumer engagement grant. The grant funds provide PFLT member stipends, mileage, educational opportunities and staff support. The PFLT mission, that was developed and adopted by the membership in 2010, reads “The Patient Family Leadership Team advocates for inclusion of the patient voice to improve health care systems and advance high quality, patient centered care.” The PFLT has advised on a number of quality improvement efforts, been a voice for patient engagement and patient centered care statewide, and supported the PCMH practices in getting their patient advisory groups off the ground. One PFLT member said, “*Our job is to talk to people who have a patient advisory group, learn what works and doesn’t work, and find a blueprint for others to do it. We are collecting information and the body of knowledge that we can go out and share with others.*”

The Patient Family Leadership Team (PFLT)

- The PFLT combines the consumer focus of the Patient Centered Medical Home initiative and AF4Q, by focusing on involving patients and family members in the 26 PCMH pilot practices. Several of the PFLT participants serve on the PCMH Working Group and help provide direction to the overall PCMH initiative. PFLT provides consumer engagement support and technical assistance to the 26 pilot practices and engages consumers to become active participants in developing the design and delivery of patient centered care. The Patient Family Leadership Team (PFLT) is supported by the general Aligning Forces for Quality grant, as well as a special 3 year Patient Centered grant Robert Wood Johnson Foundation (RWJF) awarded to 3 of the 16 AF4Q communities.

Source: Maine Quality Counts Website. <http://qid.mainequalitycounts.org/project/patient-family-leadership-team>

Strategy 1: Identify participants for advisory group

When developing an advisory group, a potential challenge is identifying the participants. It is helpful to know what has and has not worked for different advisory groups. Again, there is no single best practice, and Pen Bay and Spring Harbor found it took a few attempts before successfully forming a group. Several patient advisory groups mailed an invitation to all members of the practice. For one patient advisory group, this method elicited a few interested responses from patients. However, on the day of the meeting, no one showed up.

A more successful method was having providers extend personal invitations to patients. With this approach, providers sought out and invited patients whom they believed would make valuable contributions to the group. This “invitation” method was used because the providers knew the patients willing to help. Furthermore, a personal invitation from a trusted provider was an incentive for participants to join and participate. As one patient advisory member said, *“Many people feel honored to be invited by their provider to give feedback, and will join simply out of goodwill towards their provider.”* One important note: A “valuable” participant is defined as someone who will be comfortable speaking in the group and who has patient experiences to draw from that represent positive and negative aspects of the care.

However, a selective and personal invitation was not always an effective way to identify patients. At Pen Bay, patients were identified by the behavioral health provider. They agreed to participate yet on the day the group was meeting did not show up. In this case, the group found that by reaching out to the local NAMI (National Alliance of Mental Illness) chapter, they were able to find behavioral health patients who could encourage their peers to participate in the group.

Being viewed as a potential “valuable participant” along with willingness to participate were the primary criteria for patient advisors and more selective criteria were not yet formally applied in recruiting advisory group members. Another question or criteria for identifying group participants is whether or not all patients in the community and the diversity of perspectives present among them is being represented. This question is not yet being actively explored by the groups. As they are still in the early stages of development, identifying willing and valuable participants is an important start. However, in the future the diversity of opinions and experience in the group is an important consideration.

Regarding organizational staff participation, an advisory group member from Spring Harbor noted how important it is that patients make up the majority of the group. In her group, they learned early on that they had too many providers or “medical” and not enough patient perspectives and so they have shifted to including more patients. One of the Patient Family Leadership Team members of the PCMH Pilot said that it is valuable to have both patients representing advocacy organizations such as NAMI and individual patients who speak from their own experience and can not be redirected due to their organizational responsibilities.

Strategy 2: Set a vision and agenda for the advisory group

Development of the advisory group’s vision revolved around getting patient input on services and operations. However, each group diverged in its activities and approach. Often the vision and purpose for the group was not formally written out. However, one of the PFLT members noted that clear

definition of the group's purpose and of the expected participant contributions is an important element for long term sustainability of the group.

Organizations varied in how they developed their monthly or quarterly agendas for their meetings. Some said that organizational staff needed to be responsible for developing a vision for the group's formation and what will keep it motivated. Amistad felt that it was important for the group to direct its own process. Amistad's consumer board encompasses both an advisory role and contributes to the active management of the organization. Unlike patients at clinics, members at Amistad, a peer support and recovery organization, visit Amistad on a near daily basis. As a result, they have great commitment to Amistad and more intimate knowledge of the overall organization and its daily operations. Amistad's consumer board represents the distinction between an advisory and a decision-making board.

Regardless of who provides the agenda for the group, a strong facilitator is needed. The education of the person (clinician vs. care coordinator, for example) varied across each of the advisory groups, and it was the person's skill and experience in facilitation and not his/her job title at the organization that was important. One patient advisory group member described facilitator characteristics as follows, *"They listen and attend to the group by always scanning the room for body and facial expressions. They very strongly encourage us to share what we think. There is a lot of safety in the room about sharing our perspectives. They tell us how valuable we are at every meeting. We do not always feel like what we are providing is valuable, but they let us know every time what we are contributing."* A second patient advisory group member noted that training on group processing could be helpful to facilitators.

For all of the advisory groups, the task of setting the agenda shifted from being the facilitator's responsibility to becoming the group members' over time. At Spring Harbor, Sacopec Valley Health Center, and Pen Bay, the facilitator drafted an agenda to refer to, and then the group had the freedom to modify it. Some facilitators noted that especially early on, it was difficult for advisory group members to contribute to the agenda, as they do not see the operational issues that come up on a day-to-day basis. Thus, the facilitator, who does see these issues on a regular basis, includes them on the agenda for the group to address. It is important for other members of the group to be able to add their ideas to the agenda. One member of the PFLT said, *"Consumers and patients should always be given the opportunity to lead, even if they are not in a leadership role. Simply by asking them what their ideas are gives them a voice. It is that simple. The groups that are working best are those where the groups were asked what they would like on the agenda, or the topics for discussion."*

A Spring Harbor patient advisory member noted that leading a patient advisory group like a business meeting does not work well. She recommended that there be time built into the meetings for the group to "warm up," and for the group members to bring forward their concerns of the day. Rather than an agenda of 10 items, she suggested that it is more realistic to have an agenda of two to three topics. This was echoed by one of the facilitators who said it is important to provide some time for the group to be comfortable with one another and to "build cohesiveness and trust among the group." The agenda may be informal, such as simply listing topics on a whiteboard. Setting an agenda is important, because as one person noted, *"Without an agenda, the group may move more in the direction of a support group rather than advisory."*

Strategy 3: Make the advisory group operational

There is not one approach to structuring advisory groups that can be highlighted as better than another. Among the four advisory groups, each differed in the formal commitment its advisory group members were asked to make. Spring Harbor opted not to set any terms for participation, but has found that advisory group members voluntarily contribute on an every-other -month basis. In contrast, Sacopee Valley Community Health Center's members make a year-long commitment to attend meetings on a quarterly basis. If a member missed two meetings, then the group agreed to try to replace that person with another group member. This group also decided to develop by-laws to formalize their operations.

Most advisory groups felt that training was not a necessary component to have active and engaged participation. They believed that patients had the knowledge and ability to participate in decision making and just had to be asked. Furthermore, one facilitator suggested that by training advisory group members, there is the chance that it would limit their creativity or openness in how they participate. Member(s) of the PFLT are an exception to this, operating at a state-wide level, and not within a single provider organization to guide administrators in practices developing medical homes. As this group was operating within the organizational transformation realm and providing guidance to patient advisory groups, at least one member expressed that orientation and ongoing training were critical to members' ability to support the PCMH practices engagement with patient-centered transformation and to offer patients effective advisement on the PCMH model. Specifically, she advised training on the different levels at which patients can provide input. She felt it was important for people to know that they can provide advice at a policy level, a practice level, or through peer-to-peer support as a patient navigator. Another member of the PFLT noted that training from organizations such as the Picker Institute, a non-profit organization which sponsors education and research in the field of patient-centered care, and from experienced patient advocates is helpful to groups in understanding their role.

All patient advisory groups recognize the contributions of its members by paying a stipend of approximately \$25 per meeting. This helps elevate the status of advisory group members as well as cover gas and transportation costs to the meetings. Similar to the other groups, members of the PFLT were paid a \$75 stipend plus mileage for attending a two-hour meeting once a month. However, these members spend a considerable amount of time outside of the monthly meeting developing an orientation document and informational material, supporting PCMH learning collaboratives, and evaluating as well as supporting the PCMH engagement efforts. Under their MeHAF grant, resources were limited to pay for their time, so much of it was provided through volunteer commitment. Depending on their work and other commitments, these unpaid hours beyond the monthly meeting were challenging for some members. For this model of patient technical assistance to be sustainable and replicable, one PFLT member strongly recommended that the hours spent providing technical assistance are paid like a part-time position. Another member who had donated many hours, shared the view that *“Although being paid fairly for your work is extremely important, service work is a very good and important thing too. As the PCMH model calls for a cost efficient as well as high quality delivery system, realistically the most sustainable model for wide spread consumer engagement at the organizational and advisory group level, is a service model that provides financial support for out of pocket expenses and education along with opportunities for recognition and advancement. This would include opportunities for volunteers to*

advance into paid roles and/or to apply for related staff positions. One example of a service model that has been employed successfully is the Dana Farber Cancer Institute's Patient and Family Advisory Council (PFAC) in Boston..”⁶

Strategy 4: Consider how patient participation can benefit them personally

Patients can benefit directly from participating in an advisory group as well as being beneficial to the health care organization. For one, patients are given voice for system improvement, which they often do not have. They can feel proud of and take ownership in their important role. For some, it can be a way to build confidence in their own opinions and in speaking publicly. Participation in the group also creates bonds among the members which endure outside of the advisory group.

Participation in an advisory group can also contribute to a patient's own health and wellness. An advisory group member explained, *“Being part of the advisory committee is part of what makes me feel on an even keel.”* The opportunity to give back to the organization and those individuals that have helped them is also part of the rewarding experience. Advisory members can feel proud of their contributions to the organization. Patients feel their participation helps providers better understand mental illness and patients' experiences. One advisory member said: *“How we as an advisory committee provide input is very, very important. It is right from the horse's mouth, and health care staff needs to hear from me because clinicians and other staff may or may not have a mental illness.”* Another advisory member noted: *“I can say things, and be critical in a way that administrators and clinicians may not be able to. Not only because I am speaking from a patient perspective, but I have the freedom to speak because it is not my job.”*

One advisory group member finds being able to reduce stigma towards mental illness the most rewarding. As a speaker in the community, telling the story of someone who has experienced mental illness can be powerful and play a part in others receiving the services they need and providers better understanding of their patients' needs.

Another patient advisory group member pointed out that in a world where patients have a lot of negativity towards the health care system overall, the existence of a patient advisory group gives a very important signal to the community that providers really do care about improving services. It is easy for patients to focus on negative components of the health care system, yet having an advisory group is an avenue for patients to be heard and to know that there are individuals actively working to improve how services are delivered. It is a way for patients to know that there is a true commitment to quality. *“It is important to know that there are still people that really want to make it better - this gives you faith.”* A member of the advisory group noted that she has pride in making a contribution. *“My contribution is that when people are negative about the health care system, I have the ability to educate people that there are things that are happening and health care providers are willing to listen.”*

Strategy 5: Document and share advisory group accomplishments and activities

The advisory group is involved with a range of activities that address patient engagement and more general health system delivery improvements. The accomplishments range from giving practical input on layout and design of clinic space catering more to patient needs, to involvement in strategic planning.

Involvement can be at both the organizational and environmental levels. One patient advisory member says her advisory group has changed how the health care organization thinks about patient engagement overall. *“Instead of anticipating what patients want, and spending a lot of time on something, they have taken several steps back. They think about are we asking the right people? They ask us first.”*

Organizational

At the organizational level, patients are involved in providing guidance on operations and strategic planning. In terms of strategic planning, the advisory group can provide important insight into the new initiatives that the practice or clinic takes on. At Amistad they use open-ended questions such as: *“Assuming that money is not an object, what should be different next year?”* to generate brainstorming and new ideas. Patients also participated in strategic planning by providing insight into the decision to apply for grant funding. Sacopee Valley Health Center was more able to motivate staff and resources behind new opportunities when they knew that patients were 100 percent behind them. This ensures the clinic activities are being responsive to patients’ preferences. At the operational level, patients can bring new insight to day-to-day processes as well as to new operational initiatives. At Pen Bay, patients in the advisory group brought up their feelings of being viewed as “a bad patient” if they forgot to take medications or did not follow advice from providers. This prompted behavioral health providers to have more frequent conversations with primary care providers on how to coach and work with patients, giving them tools to help mitigate the patient’s sense of failure. This has also led to more face-to-face meetings and less e-mailing between providers.

Patients have also provided input on facility improvements. While Sacopee Valley Health Center was working on a redesign of its lobby, the patient advisory group made suggestions as to how the lobby could make them feel more comfortable and welcomed, and privacy concerns were addressed. The group made practical suggestions, such as adding a chair rail to protect the lobby walls.

Outreach on the availability of behavioral health services can be challenging for several reasons. In part, patients don’t know what types of services a behavioral health provider can provide, and how these services, along with providers, can support patients to be healthy. Also, patients are concerned about cost and payment for these services, and concerned about the stigma of receiving behavioral health. Patients have played an important role providing suggestions on how to communicate the availability of behavioral health services effectively. The Spring Harbor advisory group actively sought feedback on educational outreach materials developed by the clinic staff. This helped to ensure that the materials were attractive, encouraging, and included information that patients felt was valuable. In addition, the advisory group provided insight on the right time and place to share educational materials to patients. They talked about how the best place to put some materials, such as a pamphlet on depression, is in the exam room rather than in the waiting area. The group also discussed how the provider should determine readiness for the patient to accept information on behavioral health, as it is different for every patient.

At Pen Bay, the advisory group was encouraged to participate in the overall communications plan for the “opening” of availability of behavioral health at a new rural clinic site. The clinic staff’s initial plan was to send a mailing to all patients about the services. The advisory group suggested

that the mailing may, in fact, discourage people from using the service and be expensive to mail to the entire patient community of 8,000. Instead, the patient advisory group suggested that PenBay providers' active and direct promotion of the new behavioral health services would have the greatest impact on patient receptivity.

Environmental

Patient advisory group members can play a role in promoting integrated health beyond the clinical setting and the operations of the provider they are working with. The communications role patients have on behavioral health can take a number of forms; patients themselves can be the best educators and advocates of integration to fellow community members and providers. At Spring Harbor, members have taken their role from advisory to advocate. At events around the state, they speak to both fellow patients and providers about their experiences as behavioral health patients and the benefits of integrated care. Through these speaking engagements, they address stigma in both the provider and patient communities, educate individuals on the impact of integrated care, and advocate for the availability of integrated health. *"The education on how to improve the health care system for mental illness happens when we are out there talking to practices and telling them our story and experience of mental illness. This is when doctors and other health care providers really hear the need for improvements, when they hear it from patients like me directly."*

The PFLT works at the operational and environmental level by providing guidance on the PCMH pilot and supporting participating practices to engage patients through the formation of patient advisory groups. Members of the PFLT advocated for participating practices to incorporate their patients as partners in the PCMH transformation process. This was viewed as critical, because in the words of one PFLT member, *"the transformation activities into a medical home can be so many and so overwhelming, that patient engagement can be put on a backburner."* For this reason, PFLT members provided a critical input in the implementation of the PCMH pilot by advocating that patient engagement activities be a central part of pilot activities.

The PFLT visited some of the practices and interviewed all 26 to support and learn about their consumer engagement efforts and patient advisory group progress. They listened to the story of how, when, and where each practice engaged its patients so that the successes and challenges could be shared and collaborated on among all 26 practices. They did this by listening to the practices' concerns and providing insight into how patient engagement might help them answer their questions. For example, one practice was concerned about patients' use of the emergency room. They had been trying to work with the hospital to receive medical records and had difficulty. An alternative approach provided by one PFLT member was for the practice to engage patients as a way to collect information. She suggested that they have each provider spend one day asking two questions during the course of their visits with patients: "When was the last time you went to the ER?" "Can you tell me why you went to the ER and did not come to our practice?" From this, the PFLT member suggested the practice might get the information it was looking for in the emergency room medical records in a more timely and effective manner. By engaging and partnering with its patients in this way the practice would have the opportunity to develop alternative and better quality of care options for the patients who were

using the ER inefficiently. The end result envisioned by the PFLT was for a much richer and more meaningful relationship between the patient and provider, leading to better quality of care, avoided ER utilization and reduced downstream costs.

In addition to providing a thought leadership voice for such patient-centered care processes and practices, the important environmental level work of the PFLT included cataloging of best practices among the patient advisory groups and sharing the findings in the “Report on Patient Engagement Activities in the Twenty - Six Patient Centered Medical Home Pilot Sites” available on the Quality Counts Maine website.⁷

Strategy 6: Sustain an advisory group

Senior leadership at a health care organization must be involved to sustain an advisory group after grant funding ends. As Spring Harbor learned, the type of feedback received through the advisory group was far superior to what could be elicited from more typical patient surveys. For the information to be most useful, group facilitators suggested that the information learned from the advisory group be used to inform quality improvement processes, and that the group facilitators should be accountable to both patients and senior leadership on how their ideas were used. In three of the five organizations, senior leadership at the organization started the advisory group.

From the patient perspective, the most important element in sustaining a quality advisory group is very simple: listening. In providing advice to health care providers on how to improve services, it’s most important that patients know they are being listened to. If advisory group facilitators keep in mind this as the foundation of the advisory group’s work, then patients will stay engaged with the process. One board member said in response to the question how to ensure an advisory board’s success, “*For me, it is knowing I am being listened to.*” This was echoed by one of the PFLT members who indicated that the success of a group is predicated on the organization’s commitment to listen to and value the input of patients. If there is real commitment to include the patient voice, then there will be successful.

One patient member noted that evaluation of the group by its own members can be an effective feedback and learning tool. She suggested checking in with members one on one after they have been participating for a year or so, soliciting their feedback on how the group is functioning and what could be done to improve it.

B. Patient Engagement through Community Education

Advisory groups are one method for outreach and soliciting patient input. However, Tri-County Mental Health Services took the approach of community education as a way to engage both current patients and the general community. They held a series of monthly educational community dinners on integrated care and behavioral health. Planning of the meetings relied on advisory group members suggesting topics and priorities for the educational sessions at the community dinners. Topics at past dinners included *Celebrating National Recovery Month* and *Understanding Trauma*. As many as 50 people attend each dinner.

Dinner speakers address a topic from multiple perspectives – those of a patient, medical provider, a behavioral health provider, and a dental provider – and contribute to new understanding for the patients, providers, and general community members attending the event. Each dinner provides ample time for

discussion and questions. One question that was asked at a community dinner was, “What are co-occurring disorders and how are they treated at Tri-County Mental Health?” Another asked for further definition and explanation of the term “behavioral health.” The audience member who asked the question said she understood behavioral health as specifically addressing problematic behaviors (hitting, smoking, etc.). This prompted a discussion of the term, and Tri-County clinical staff members provided their definition of behavioral health as being inclusive of services to address mental health and substance abuse conditions.

In addition to a special topic of the month, the meetings are a way for Tri-County to describe the concept of integrated services, the breadth of their services, and their partnerships with local medical providers to deliver integrated services. Through these questions and answers, the providers receive feedback on what community needs and questions are, and how they can improve services. Their feedback stimulates changes to policy, procedures, and implementation.

Lessons Learned/Tips on Patient Advisory Groups:

- Extend personal invitations from providers to patients to participate in an advisory role. This has proven to be an effective method of recruiting members to a patient advisory group.
- Articulate patients’ role in the advisory group, along with the group’s objectives, at the start.
- Ensure that the group composition has more patients than providers and staff.
- At every meeting remind participants of the value they bring to the organization through their advice and input.
- Be persistent and try several tactics to identify patients for an advisory group; there is no single best way.
- Use an agenda with lots of “white space,” so that advisory members have room to provide their input on agenda items and have time to warm up with the group.
- Hosting community dinners with an educational component followed by discussion is an alternative method to receive feedback on integrated services that includes diverse voices in the community.
- Be willing to listen to and act on patient suggestions; the stronger the commitment of the administration and staff to the patient voice, the more engaged patients will become.
- Patients can play an active role in advising without any training, but organizations such as the Picker Institute can provide resources and training specifically on the topic of patient engagement

V. CONCLUSION

Each of the six organizations said that engaging patients improved staff and patients being able to work as a team as well as improved and forged new bonds through integrated services. Each organization ventured out on its own with no instruction manual, so many attempts to modify and refine how they approached each of these strategies were necessary. Shared decision making was the one patient engagement strategy that two of the organizations said their staff needed more training on to improve skills and ease engaging patients.

At the organizational and environmental levels of engagement, members of the Patient Family Leadership Team (PFLT) raised several important discussion points for further developing the work of patient engagement. First, there is a need to educate patients about the various levels of care delivery and policy development where they can have a voice. This includes the organizational, system improvement, and environmental or policy development levels, so that patients are able to employ their voice where they feel most comfortable and are able to contribute most effectively. Many patients do not realize that there are ways they can provide input on both organizational and environmental levels. Secondly, if patient advisors are to become part of a professional team spreading the movement of patient engagement, many patient engagement volunteers and staff trained in and dedicated to patient engagement are required. In cases where more time is needed than is available through volunteer capacity such as in providing technical assistance in the PFLT, the option for expanded roles for volunteers into paid and/or new staff positions should be explored. Finally, at the patient advisory level, one patient member noted that it is important to acknowledge that having a patient advisory committee is radical for many clinical and administrative staff, as it cedes some control of the organization to patients. This is not always easy. It may require the organization to acknowledge and confront its consumer empowerment related fears and hesitations, so that in a transparent and effective manner its patient advisory group(s) may operate as valued and equal partners in realizing quality improvement and patient-centered care transformation.

All acknowledged that while difficult, efforts toward patient engagement were deeply rewarding. However, on each level of care – patient experience, clinical microsystem, organizational, and environmental – integrated care settings must commit to fully embracing, listening to, and valuing the patient voice.

ACKNOWLEDGEMENTS

JSI would like to thank the contributions and time for interviews from the staff of Amistad, Maine Pen Bay Healthcare, Primary Care Association, Maine Quality Counts, Sacopee Valley Health Center, Spring Harbor Hospital, Tri-County Mental Health Services, and a special thank you to the patient advisory group members who volunteered to be interviewed: Poppy Arford, Kait Bragdon-Roe, Patti White, and Michael White.

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Appendix A: Summary Description of patient engagement activities at six organizations in Maine

	Site 1: Sacopee Valley Health Center	Site 2: Amistad	Site 3: Tri-County Mental Health Services
Practice Setting	Federally Qualified Health Center	Member-driven organization for individuals with diverse behavioral health conditions providing daily support, activities, and emphasis on healthy living.	Community Mental Health Agency
Population Served	Rural population ranging from children to adults	Adults with a range of mental health and substance abuse conditions with an emphasis on those with high behavioral health and physical health needs.	Rural Adult and pediatric patients
Patient Engagement Activities	Patient welcome visits, care facilitator follow-up calls, patient advisory group	staff as valued members of patient-centered care team	Community Dinners, patient advisory council
Integrated Care Activities	Sacopee Valley Health Center has been providing co-located services for 25 years and launched its integrated program in 2005, establishing at that time the role of the Behavioral Health Consultant (BHC). The BHC is a licensed clinical social worker who works as a member of the medical team and sees patients in 15-20 minute intervals. The focus is teaching patient tools to cope with conditions more effectively. Some conditions may include: anxiety, depression, chronic Consumer board, assistance to primary care practices on how to train front desk	Amistad is a consumer run organization (all of its board members are consumers) serving clients with severe and persistent mental illness. To address the challenges faced by the severely mentally ill that lead to premature morbidity and death, Amistad has developed simultaneous programs to both engage their members in medical care and change their daily health habits. The first component of the program, Peer Patient Navigation, is based on the concept that members will	Tri-County Mental Health Services and Rumford Hospital have entered into contractual relations that place licensed therapists from Tri-County within three primary care clinics that are owned and operated by Rumford Hospital. These therapists partner with the primary care medical staff to provide integrated mental health and substance abuse counseling services in a co-located arrangement. The medical practices bill for the behavioral health services, usually using health and behavior coes.

	Site 1: Sacopee Valley Health Center	Site 2: Amistad	Site 3: Tri-County Mental Health Services
	pain, diabetes, and hypertension.	be more likely to see medical and behavioral health providers with the support of a peer. The peer navigator assists with scheduling appointments, taking notes, and providing follow up during and after the appointment, as well as transportation if necessary.	Patients served at the clinics were also provided access to a psychiatrist from Tri-County via referral and on a provider consult basis. Case management and care management services were provided on-site at the primary care clinics as well as by referral to staff off-site at Tri-County. Patients with high level needs were seamlessly integrated into community mental health services.
Location	Rural Western Maine, Parsonsfield	Portland, ME	Rural Western Maine, Rumford and surrounding towns

	Site 4: Spring Harbor Hospital	Site 5: Mid-Coast Mental Health
Practice Setting	Medical and behavioral health care system	(Pen Bay Healthcare) Centered Medical Home Pilot Community Mental Health Agency Quality Improvement Organization
Population Served	Adult and pediatric patients	Patient advisory council
Patient Engagement Activities	Patient advisory council	<p>feedback. The Patient and Family Leadership Team includes several patients who act as ambassadors to the pilot practices on the benefits of a patient advisory council and how to develop one.</p> <p>Adult and pediatric patients</p> <p>A Patient and Family Leadership Team was formed to provide high-level guidance to the participating practices on how to better engage patients through the formation of patient advisory councils and soliciting patient</p>

Integrated Care Activities

Spring Harbor Hospital is a member of MaineHealth, which established the Mental Health Integration Program (MHIP), focusing on partnerships between primary care and mental health practices. The purpose of the project is to develop the capacity for integration through matching primary care practices with mental health organizations and

Mid-Coast Mental Health (MCMH) is a community-based mental health clinic affiliated with Pen Bay Healthcare that provides a broad range of behavioral health services to those with mild to severe mental health and substance abuse conditions. MCMH provides outpatient services at their clinic in Rockport, ME, and outpatient/inpatient

The Patient Centered Medical Home is an approach to improving the delivery of primary care to encourage more integrated services for the patient and improve the patient experience of care with the ultimate goal of improving patient outcomes. Twenty-six primary care practices throughout the state of Maine have agreed to participate in a

Site 4: Spring Harbor Hospital **Site 6: Mid-Coast Mental Health**
Site 6: Quality Counts Patient

providing training and technical assistance to the matched pairs. Twenty primary care practices were involved in the project between 2005-2010. Practices are involved with the MHIP for 12-18 months. Staff develop the integration capacity of the practices through offering quarterly Learning Sessions. In between sessions, grant staff, or other MHIP staff, offer remote (through teleconference) and on-site technical assistance to the practices.

services at independent community settings around the region, including those that are part of the Pen Bay Healthcare umbrella. Mid-Coast Mental Health (MCMH) has integrated its behavioral health specialists into five (5) primary care clinics as well as three schools in the Rockport area. Four (4) of the primary care clinics are part of the Pen Bay Health Care network and one (1) is a stand-alone, private practice. MCMH has placed an LCSW therapist at each of the Pen Bay primary care clinics and they have placed a psych NP at the private practice setting.

pilot of this approach. Through participation, these practices are provided training, coaching, and support in transforming their practice to embrace the principles of a medical home. Over the four year pilot, practices receive financial support through the joint support of private commercial insurance plans, Medicaid and Medicare who are supporting the practices through payment of \$6 per member per month reimbursement to the provider and a \$3 per member per month that supports Community Health Teams. The community health teams are multidisciplinary (nurse, behavioral health, etc.) teams that are designed to support and work with the highest need patients who have the most frequent use of the hospital and the emergency room. In year one, the project accomplished the initial goal to have each of the participating practices attain National Committee for Quality Assurance (NCQA) Certification.

Location

Westbrook, ME and towns across Southern Maine

Coastal Maine, Rockland and surrounding towns

Statewide