Muskie School of Public Service

Engaging Patients in Health System Transformation: The Experience of the Maine Health Access Foundation's (MeHAF) Advancing Payment Reform Initiative

June 2015

Barbara Shaw, JD, Andrew Coburn, PhD, Kimberley Fox, MPA

OVERVIEW

In 2001, the Institute of Medicine (IOM) identified patient centeredness as one of six essential aims of "a new health care system for the 21st century".[1] Since that time, we have begun a gradual shift from a professionally driven system toward one that is more "patient centered" or "consumer centered," recognizing and incorporating patients' perspectives in decisions in clinical care, delivery system, and policies. As the health care system responds to new payment approaches and positions itself to achieve the Triple Aim (i.e. better care, lower cost, enhanced patient experience), it is important to assess how organizations that are moving to advance health care service delivery and payment reform are integrating patient engagement into the health system transformation process.

Since 2011, the Maine Health Access Foundation's Advancing Payment Reform initiative has funded 13 health system transformation projects. Diverse in their approach, each has undertaken efforts to achieve greater patient engagement ranging from involving patients and families as informed and active participants in their own health care (e.g. shared decision making, self-management) to involving patients at the organizational or policy-level through consumer advisory boards and other means to provide guidance for health system transformation.

This brief summarizes the experience of these grantees in developing and implementing strategies to engage patients in payment reform and delivery system redesign.[2] The purpose is to identify common themes and lessons within and across these initiatives to inform future patient engagement efforts.

Key Observations

- Patient engagement requires significant changes in professional and organizational norms and culture that are difficult to achieve and will likely take time.

- The strategies and tools for effecting the necessary changes to support greater patient engagement are limited.

- Changes in financial incentives for patients/consumers and providers are likely to accelerate efforts to achieve greater patient engagement.

- Efforts to promote patient engagement are heavily focused on healthcare. With a growing acknowledgement of the links between family, community, healthcare, and health, broader strategies and tools that apply to more than healthcare will be needed.

For more information on this study, please contact Andrew Coburn at andyc@usm.maine.edu

1 Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: National Academy Press; 2001.
2 See Appendix 1 for a list of grantees with organizational acronyms and brief project descriptions.

BACKGROUND

MEHAF's Advancing Payment Reform and Patient Engagement

MEHAF's Advancing Payment Reform initiative was launched in 2011 and concluded in early 2015 with three cohorts of projects funded during this period. The goal was to stimulate and assess innovative payment and delivery system reform strategies in Maine. The funded projects were diverse in their reform goals and strategies. The unifying objective across grantees was to fundamentally change the payment, and delivery systems to improve value and to address the needs and issues of uninsured and medically underserved individuals in their change strategies.

Patient engagement was a core expectation throughout the initiative with focused attention during quarterly learning collaborative/grantee meetings. National experts on patient engagement presented in several collaborative meetings. Beverley Johnson, President and CEO of the Institute for Patient and Family Centered Care discussed tools to help grantees assess their organizational readiness to engage patients and families and then implement strategies to increase engagement.[3] Judith Hibbard, PhD, MPH, Professor of Health Policy at the University of Oregon, also presented to the collaborative on recent findings and research related to the Patient Activation Measure© (PAM) tool, which several grantees have used in their projects.[4] And finally, over the course of the learning collaborative's focused discussion of patient engagement, five grantees presented information on their patient engagement efforts to the larger group.

Evaluation Approach and Conceptual Framework

Because of the diverse aims and design of the individual projects, our overall evaluation goal was to provide MeHAF and the grantees with a broad-based and rapid cycle "program assessment" focusing on the implementation and early results of the projects in addressing the core questions of the initiative (sidebar).

The evaluation team has prepared a series of briefs on selected cross-cutting issues affecting all grantees. The first examined issues involving organizational change as a core challenge in health system transformation; the second discussed grantees' experiences in accessing and using health data to support system transformation.[5]

This third brief examines the role of patient engagement in system transformation. Patient engagement is conceptually most closely related to Core Questions 3 and 6.

3 Institute for Patient- and Family-Centered Care. *Resources*. [web page]. 2015. Available at http://www.ipfcc.org/resources/index.html.

4 Hibbard JH, Greene J. What The Evidence Shows About Patient Activation: Better Health Outcomes And Care Experiences; Fewer Data On Costs. *Health Aff (Millwood)*. 2013;32(2):207-214. The PAM tool is a product of Insignia Health.

5 Shaw B, Coburn A, Fox K, Rogers E. *The Role of Organizational Change in Health System and Payment Reform*. Portland, ME: USM Muskie School of Public Service; 2013. Issue Brief. Shaw B, Coburn A, Fox K, Gerstenberger, A. *Accessing and Using Health Data to Support Health System Transformation: The Early Experience of MeHAF Payment Reform Grantees*. Portland, ME: University of Southern Maine, Muskie School of Public Service;2014. Issue Brief.

Core Questions for Evaluation:

1. How are the strategies and activities of these projects targeting and achieving measurable healthcare cost containment?

2. Have the projects had an impact statewide, regionally, or locally?

3. How is the MeHAF initiative preparing stakeholders (e.g., health systems, providers, consumers and other organizations) to meet the new payment and delivery system reforms projected in the ACA?

4. What barriers and opportunities have the projects encountered?

5. How have barriers and opportunities been addressed, and what are the lessons for others?

6. How have the needs of uninsured and medically underserved people been addressed by each project? Are there specific lessons about how best to include these populations in payment reform efforts?

7. Is there synergy between and among projects? How are projects changed or augmented by coordination with the other grantees' work?

8. Based on the lessons from these projects, how could the effectiveness and impact of this initiative be enhanced?

The variety of projects and the multiple strategies by which grantees approached patient engagement necessitated the use of a unifying framework to characterize and describe the grantees' activities. To this end, we used a definition and framework of patient engagement proposed by Carman et al. which articulates a multi-level, multi-stakeholder perspective:

"Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system –direct care, organizational design and governance, and policy making –to improve health and health care." [6]

This definition and their accompanying framework identifies a continuum of patient engagement that can be characterized in terms of both levels and type. The framework is constructed around the different settings in which patient engagement can occur, from the clinical encounter to the health care organization and the community or policy level (Table 1). Specifically, the framework distinguishes between engagement at three levels: "direct care", "organizational design and governance" and "policy and community engagement". In addition, it posits a continuum of types of engagement from "consultation" to "involvement," to "partnership and shared leadership". In the consultation column, patients are informed (consulted) but have limited power or decision making authority. The provider or health care system sets the agenda. Information flows to patients and then back to the system. At the other end of the continuum, engagement is characterized by shared power and responsibility with patients as active partners in setting agendas and making decisions. Here information flows bi-directionally and decision making responsibility is shared. The middle column, "involvement" represents an intermediate level of bi-directional information flow and increased patient decision making authority.[7]

The evaluation team used both group meetings with grantees and semi-structured interviews to gain an understanding of grantees' patient engagement strategies and activities. Grantees completed an initial brief questionnaire identifying patient engagement strategies and activities that were part of their MeHAF-funded project or their broader transformation efforts (Appendix 2). Using the patient engagement framework, the team then facilitated a discussion with grantees at one of MeHAF's quarterly collaborative learning sessions/grantee meetings in which responses were briefly reviewed sparking

additional discussion. Using the questionnaire responses and the grantee discussion, the team then developed a semi-structured interview protocol (Appendix 3) and in September and October 2014 conducted eighteen telephone interviews with the project directors and staff members charged with patient engagement responsibilities.

Guided by the framework illustrated in Table 1, our interviews asked grantees about their patient engagement efforts across the three levels of direct patient care, organizational design and governance, and policy making and community engagement. We also asked grantees about factors identified in the literature that may have affected the level and type of patient engagement, including patient attitudes and beliefs, health literacy, functional capacity and perspectives; provider and organizational culture and policies and practices; and broader system-level regulations and policies. Based on grantee surveys and interviews, we categorized the grantees by the different levels of engagement defined in the framework.

We analyzed our questionnaire and interview data to identify key themes across the different levels of patient engagement. These themes are discussed below with examples drawn from grantee experiences both with their MeHAF-funded projects and their broader transformation efforts. This broader lens was used for two reasons. First, many of the MeHAF-funded projects are thoroughly interwoven with their primary organizational strategies and activities, making it impossible to disentangle the patient engagement activities specific to the MeHAF-funded project. Second, the grantees represent a broad cross-section of organizations where there have been a number of efforts focused on improving patient engagement in recent years. As such, some have relatively more experience than others in undertaking patient engagement initiatives. We wanted to capture that breadth in this brief.

In the final section of the brief we discuss the implications and lessons of the experience of these grantees for efforts to enhance patient engagement in health and payment reform initiatives going forward.

---

6 Carman KL, Dardess P, Maurer M. et al. Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. *Health Aff (Millwood)*. 2013;32(2):223-231.

7 Ibid.

Table 1: A Multi-Dimensional Framework for Patient and Family Engagement in Health and Healthcare[8]

Continuum of Engagement

→

Levels of Engagement	Consultation	Involvement	Partnership and Shared Leadership
Direct Care	Patients receive information about a diagnosis	Patients are asked about their preferences in treatment plan	Treatment decisions are made based on patient preferences, medical evidence and clinical judgment
Organizational Design and Governance	Organization surveys patients about their care experiences	Organization involves patients/consumers as advisors or advisory council members	Patients/consumers co-lead safety or quality improvement committees
Policy and Community Engagement	Public agency or community organization conducts focus groups with patients to ask opinions about health care issues	Patient /consumer recommendations about priorities are used by public agency or by private organizations to develop policies	Patients/consumers have equal representation on committees that make decisions about allocating resources to health programs

Source: K.L. Carman et al.

Levels and Types of Patient Engagement Activities

As shown in Table 2, all of the MeHAF grantees' projects included patient engagement elements in at least one of the three levels --direct care, organizational design, and policy or community engagement. Several are engaging patients at more than one level. Most grantees are largely engaging patients or consumers in "consultation" or "involvement" roles; only a few were involving patients at the partnership or shared leadership level.

Direct Care

Seven of the 13 grantees focused on activities to engage patients in direct care using a variety of strategies. Maine General Health's volunteer Peer Navigator program links someone who has experienced a chronic condition with other patients to provide support for chronic care self-management. Maine General is also working to measure patient activation and self-efficacy to target their efforts to those patients most ready to participate or most likely to benefit.

Other health systems, including Mercy, the Franklin Community Health Network (Franklin),

The Aroostook Medical Center (TAMC), and Eastern Maine Healthcare System (EMHS) focused on engaging high-need patients, including those that frequently use the emergency department or who are uninsured. Their initiatives used a variety of strategies, including coordinated outreach and "natural community supports" provided by multiple partnering organizations; use of "Special Care Plans"; use of the PAM tool to inform care coordination efforts and to assess how patient activation affects outcomes; and use of community-based care, nurse navigation, and coaching strategies specifically focused on linking uninsured patients applying for charity care with primary care providers.

With funding from MeHAF, Quality Counts developed multi-disciplinary Community Care Teams (CCTs) to support patients of primary care practices participating in Maine's multi-payer Patient Centered Medical Home Pilot, the Medicare Advanced Primary Care Practice (MAPCP) demonstration, and MaineCare's (Medicaid) Health Homes initiative. The CCTs use patient self-management approaches to engage high need patients in their care. Quality Counts provides oversight and technical assistance to the CCTs and ensures that patient engagement is a meaningful element of their work. The Maine Primary Care Association (MPCA) has also been using the CCTs to provide similar support for Federally Qualified Health Center patients.

---

8 We have modified the original framework to add "community engagement" to emphasize this aspect of the work of several MeHAF grantees in this area.

Table 2: MeHAF Grantee Patient Engagement Activities by Level and Type

→ **Continuum of Engagement** →

Level of Engagement	Consultation	Involvement	Partnership and Shared Leadership
Direct care	Maine General Health (MG), Quality Counts (QC), Mercy, The Franklin Community Health Network (Franklin), The Aroostook Medical Center (TAMC), Eastern Maine Healthcare System (EMHS), MaineHealth (MH), Maine Primary Care Association (MPCA)	MG, QC, Mercy, Franklin, TAMC, EMHS, MPCA	Mercy
Organizational Design and Governance	MH, Maine Community Health Options (MCHO), MG, MaineCare/QC	MCHO, MG MaineCare/QC	MG
Policy and Community Engagement	Maine Health Management Coalition (MHMC), MCHO, MCD Public Health/Somerset Public Health (MCDPH) , MaineCare, HealthInfoNet (HIN), Maine Medical Education Trust (MMET)	MHMC, MCHO, MCDPH	MCHO, MCDPH

Organizational Design and Governance

Many of these same grantees have also engaged patients at an organizational level focusing on practice design, governance, or other issues. For example, MaineGeneral established practice-level patient and family advisory boards/councils to inform system leadership regarding practice improvement strategies and activities. Quality Counts requires all practices participating in the multi-payer PCMH Pilot, MAPCP, and Health Homes initiatives and CCTs to have patient advisory boards to inform these new care models, MaineHealth conducted focus groups with patients to explore their priorities for primary care. This information was used to inform the design of primary care practice models ("lab practices"). These "lab practices" will test new staffing and patient engagement approaches, with results intended to guide changes in all MaineHealth practices.

Policy and Community Engagement

Maine Community Health Options (MCHO) is a new health insurance plan established with federal loan support made available through the Affordable Care Act. Consistent with its status and organization as a health insurance cooperative,[9] MCHO recently held elections for a consumer-led board of directors. In addition, MCHO regularly seeks feedback from consumers and policy holders about benefit design and other features of their plan, including, for example, their consumer/patient care management strategies (e.g. use of health risk assessments, self-management protocols). As part of their MeHAF-supported project, MaineCare and Quality Counts sought input on the design of the MaineCare Behavioral Health Homes from consumers serving on an advisory committee.[10] Through their Pathways to Excellence program, the Maine Health Management Coalition (MHMC) publicly reports physician and practice-level quality measures. MHMC has done consumer testing to select consumer-relevant measures of performance for payment reform. They have also involved consumers in workgroups related to Accountable Care Organization (ACO) development, Value Based Insurance Design (VBID), and health care costs to ensure that recommended system changes and measures consider consumer and patient perspectives and needs. HealthInfoNet (HIN) has also engaged consumers on its advisory board in the design of its health information exchange to address concerns about release of confidential health data and to provide input on the design of patient portals to support patient directed care. And finally, in their MeHAF-funded project, Medical Care Development Public Health/Somerset Public Health (MCDPH) recruited and engaged employers and employees to

---

9 Authorized and funded in the Affordable Care Act, Consumer Operated and Oriented Plans (CO-OP) have been established to offer individual and small group coverage a qualified health plan through the federal and state marketplaces.
10 Behavioral Health Homes are a partnership between a licensed community mental health provider and one or more Health Home (primary care) to manage the physical and behavioral health needs of eligible adults and children.

plan worksite wellness programs, policies, and activities targeted to small, rural employers.

PATIENT ENGAGEMENT KEY THEMES AND OBSERVATIONS

Despite differences in grantees' patient engagement strategies and activities, a number of consistent themes emerged from interviews with grantees regarding their approaches and experiences. These key themes, which reflect the lessons learned across the MeHAF funded projects, are summarized below in each of the three levels of engagement noted in Tables 1 and 2. Quotes from grantees are included to exemplify the themes or enrich the observations.

Direct Care Level of Engagement

All of the grantees whose patient engagement activities were in the "direct care" category underscored several fundamental components to the theme of empowering patients. While the theme of empowerment of patients or consumers applies most directly to the "direct care" level of patient engagement, it applies to the other two levels of patient engagement as well.

> ► **Empowering patients and engaging them as equal partners is a critical element for success. Patient engagement occurs as a result of building a trusting relationship between the provider and patient that is based on mutual respect and understanding.**

Grantees recounted how they learned to listen to patients, hear their priorities, and understand their concerns. They noted that this process reveals how their assumptions and values, which are grounded in their professional and organizational viewpoints, often do not square with patients' perceptions about the health care system.

Franklin noted that it is common among vulnerable and non-engaged patients to believe that "health care is in the hands of their doctor or in the hands of the hospital and they access it when they need it, but they don't see themselves as involved in their [own] health care."

> ► **Setting goals that are attainable and meaningful to the patient and that address their values and needs is essential for patient engagement.**

In order for patients to become the drivers of their own health and health care, they need to experience positive change and perceive the value of the engagement. It is particularly important for patients from groups where relapse and recidivism are common to see results. Achieving attainable goals also enhances the patient's perception of provider accountability; otherwise patients lose confidence in their provider.

Consistency of approach is critical to creating mutual trust between provider and patient:

Several grantees noted that a "warm touch" is needed for those hardest to reach. For example, community health center staff have a "daily huddle" to identify which patients may have more

"When a patient experience is good for the patient, it may not always equal what I think of as good [care]. I don't consider emergency room care good care, but for a patient, they may consider that patient-friendly. They're happy with that...Patient friendly to [the patient] meant he could go when he could get a ride. It also meant that nobody passed judgment on him because he wasn't going to see the same person [each time]. He said 'When I go to the doctor's [office] they give me 'that look.'"

-Franklin

"Every time we meet with them, we talk about the steps we are taking to achieve the goals and outlining exactly what we're going to do and what they're going to do....We want them to be taking responsibility for whatever steps they need to take to achieve their goals so they can 'fish for themselves,' so to speak."

-MaineGeneral

trouble with access and then reach out to them. At Mercy's weekly Medical Neighborhood meeting participants ask, "Who are you worried about today?" Outreach workers go out in the community, make home visits, visit tent city homeless sites in Portland, and accompany patients to their initial appointments.

Mercy recounted the example of a patient with profound mental illness who previously averaged 154 annual visits to the emergency department and was seen only seven times in the past year. Her care has moved from an acute setting to a medical home. Most significantly, she receives daily peer contact through the Medical Neighborhood. Mercy noted that daily contact with peer support has improved sobriety among some chronic alcoholics.

Organizational Design and Governance Level of Engagement

> ► **Patient engagement requires accountability and demonstration that patient input matters**

TAMC developed a Special Care Plan for patients seen in the Emergency Department to document the patient and provider responsibilities and to guarantee consistency of care wherever the patient later presented for follow-up care or treatment.

Achieving greater patient engagement in organizational design also requires agreeing upon achievable goals that can be acted upon so that patients feel their input has resulted in some change.

> ► **Plan for cycles of patient and consumer interest in engagement and take advantage of actionable moments.**

Grantees working on patient engagement at the organization and practice design and governance levels found that recruiting patients and consumers at the right time, when it is most meaningful to them, is essential to successful engagement.

Participation by patients and consumers in advisory groups is a highly dynamic process, characterized by a cyclical turnover of participants. Grantees involved with forming and sustaining such groups reported that they had to plan ahead to replace volunteers who move on. Successful participation also means assessing the kind of information and supports community volunteers need.

All grantees acknowledged that recruiting volunteers from vulnerable populations presents additional challenges, including health issues, child care, transportation, time constraints, confidence in group participation, and health literacy. Grantees noted that organizations need an engagement process with realistic expectations, allowing for alternative and more flexible methods of participation such as seeking feedback or convening focus groups at the point of care rather than expecting patients to come in for scheduled meetings.

"Practices need to make sure that they're showing that they're listening and acting on [patient recommendations], even if they can only do a small piece…the feedback loop is really critical."

- MPCA

"…you need to find someone who is engaged in their own process early on. That's when the timing is right, when they're going through their own process or improving their own self-management skills and then they will help others because they're doing well [themselves]."

-MaineGeneral

"...it is important to understand the support that folks need to participate meaningfully. What do they need to know? They don't want to become experts in behavioral health, but they do want to be involved."

-MaineCare

► Obtaining health system and provider buy-in for patient engagement is challenging.

All grantees agreed that successful patient engagement and patient centered care requires strong support from organizational leadership and an explicit organizational mission to guarantee necessary resources and staffing. Since many engagement activities are inadequately reimbursed (or not at all), it is essential that senior leadership embrace and support these efforts until better financial alignment exists between patient engagement and the payment system.

While all grantees had their organization's support for patient engagement activities, many sensed some organizational skepticism about whether the 'return on investment' of patient engagement is sufficient to warrant the attention of senior leaders who are juggling competing organizational priorities. Two grantees are focused on addressing this skepticism. EMHS aims to show how care coordination reduces costs and intends to demonstrate return on investment for coordination and care management. Maine Health is developing financial models of primary care practices relying on team-based care and using capitation models of payment. Maine Health is developing several "lab practices" to test new primary care team designs, providing up front support and infrastructure for a comprehensive care team.

Many grantees reported that meeting patients where they are and engaging them in organizational change requires a fundamental shift in the doctor-patient relationship from one that has largely been paternalistic to one that is more collaborative. This shift requires skills that many physicians lack and don't completely believe are effective. While most direct care grantees noted increasing support from providers over the course of their projects, providers were not generally viewed as champions or leaders of patient engagement. While many providers have grown to appreciate the value of care coordination in helping to assemble resources that a patient needs, they often view themselves as separate from this activity.

Quality Counts, a grantee engaged with ongoing provider education and support for health system transformation, noted the confusion among providers on the topic of patient engagement. Their concerns include: diversion of their time and resources, divergence from the traditional medical culture that does not consider patients as active participants, change fatigue (even if they perceive it as a worthwhile endeavor), and the challenge of engaging patients who do not have sufficient skills or understanding. Grantees noted Quality Counts' important role as a convener, bringing providers and patients together to improve competencies necessary for both groups to be active and effective participants in patient engagement and team based care.

While much attention is focused on patient activation and measuring a patient's level of ability to engage in his health care, one grantee emphasized that "practice activation" is equally important – getting providers ready to partner and collaborate with patients in both the direct care and practice redesign setting. EMHS expected that patients who were using the emergency

MaineGeneral consulted with Bev Johnson and her organization, Institute for Patient and Family Centered Care in the early stages of their project, to guide them in making organizational changes (mission statement, goals, job descriptions) consistent with prioritizing patient engagement. MaineGeneral formulated a 3-year plan for patient engagement. This leadership and organizational planning has led to organizational changes that have created a fertile environment for expanding patient engagement. In the context of the framework in Table 1, MaineGeneral is an example of a system that is moving to shared leadership and partnership in its patient engagement activities in organizational design and governance.

department and walk-in care would score low on the Patient Activation Measure (PAM). To their surprise, they found that two-thirds of the patients using walk-in health care centers were "highly activated" according to the tool. Furthermore, for this group of patients there was no correlation between activation levels and having a primary care physician. They concluded that patients take steps that make sense to them to obtain care when they need it (an "activated" behavior) and that perhaps it is the primary care practices themselves that are not sufficiently "activated" to receive and engage patients in a manner and at a time and place that helps patients understand and value a regular primary care connection. These findings have been brought to the attention of administration and physicians to consider changes that may be needed.

MaineGeneral's peer navigator program has demonstrated to some physicians the value of patients learning from their peers. While the medical provider remains the primary educator for the patient about their chronic condition, the patient learns from peer supports about the methods and ways to integrate that information into their own lives and manage their disease successfully. Such experiences have shown these providers that the responsibility for patient care does not rest on their shoulders alone and demonstrates the power of the community supports in augmenting direct care.

> "The docs step back and say 'We appreciate [care management] because it allows us to practice our craft, [which] is medicine. We shouldn't be involved in trying to connect these patients to resources.'"
>
> - TAMC

Maine Medical Education Trust (MMET) developed a survey of the Maine Medical Association membership to learn about Maine physicians' attitudes about health reform in general and physicians' view of performance measures. While the survey did not specifically ask about patient engagement efforts, the results indicated that only a small minority (16%) consider widely used performance measures reliable and meaningful. A majority expressed concern that the measures were additional burdens interfering with patient care but also expressed willingness to embrace measures if they can be shown to improve care and/or access. The surveyed physicians did not view financial incentives as necessary to provide good care. Physicians feel more comfortable with physician-led organizations and initiatives, such as the American Board of Internal Medicine's project, Choosing Wisely.[11]

While several grantees expressed optimism that provider attitudes are changing, particularly among those more recently trained and those employed by hospitals and health systems, there remains much work to change from the traditional provider-patient relationship to a more collaborative and shared decision-making approach. As noted by more than one grantee, changes in medical education and moving away from reliance on fee-for-service payment are all necessary elements for the desired culture transformation.

As patient engagement has assumed a higher priority, research and health advocacy organizations have focused on the professional and organizational competencies necessary for

---

11 Choosing Wisely, an initiative of the American Board of Internal Medicine, aims to promote conversations between providers and patients by helping patients choose care that is supported by evidence, not duplicative, free from harm and truly necessary. Choosing Wisely has developed lists (Things Physicians and Providers Should Question) which represent specific, evidence-based recommendations providers and patients should discuss together in order to make wise decisions about the most appropriate care based on their individual situation.

Mercy's integration of neighborhood partner organizations in the medical setting (e.g. Amistad, a social club for mental health consumers, provides peer support to patients in the Mercy emergency department) is an example of shared leadership and partnership reflected in the continuum of engagement in both direct care and community levels of engagement (Table 1).

MCDPH/Somerset Public Health is the MeHAF grantee most involved with community engagement around employee health and wellness and demonstrates what shared leadership looks like in community engagement. Their original project in Somerset County involved small employer and employee engagement addressing environmental health policies in the workplace and the community. The program links employee and worksite wellness and community health with economic vitality. Key principles in engaging community partners include: environmental changes and policies, providing education, risk assessments and support for changing behaviors. The project aims to link the concepts of economic health and public health by identifying common community goals. In this unique project, businesses and chambers of commerce are beginning to see their shared responsibility for the public's health and the vital role they play to complement the health care system. Over the course of the MeHAF initiative CDPH/Somerset Public Health obtained funding from a Centers for Disease Control and Prevention Community Transformation grant to scale up from a single-county, small employer-focused "micro-wellness" project to a statewide program involving Healthy Maine Streets in 19 communities and 200 businesses.

patient engagement and have developed guidance for organizations to become more patient centered. The Institute for Healthcare Improvement in particular has provided guidance for engaging providers.[12] Research is also starting to identify and study the competencies for providers and patients necessary to optimize specific patient engagement strategies, such as shared decision making.[13]

Policy and Community Level of Engagement

► **Patient engagement requires a shift from a medical to community based approach to care.**

Many patients have social and other nonmedical needs that often must be addressed before any meaningful patient engagement in health issues will occur. Respondents from Franklin noted that many patients in self-described poor health are burdened by so many other psychosocial issues they do not view their health as a major concern: "That's a person who isn't necessarily engaged in their health because they're so engaged in just trying to make it day to day."

Connecting and collaborating with community resources is essential. TAMC observed, "It takes a village to take care of the patients in our community who have fallen through the cracks."

Noting that the medical model will not solve problems of the uninsured, many grantees indicated that successful patient engagement has involved building relationships with community programs. Several grantees noted the importance of the community reach of their projects. Mercy's Medical Neighborhood includes community partners who connect the hospital and health system to the population they serve, including Amistad, a social club for mental health consumers, Milestone, a wet shelter for alcoholics, Health Care for the Homeless, and the Preble Street homeless shelter and resource center. Many of the necessary resources for patients to improve their health, including general assistance, food pantries, housing resources are provided by these and other community partners.

Grantees noted that social workers are important members of the care team to address patients' social and non-medical problems. Quality Counts' CCTs use a multidisciplinary team in the care planning process, including the patient, family support, friends, community services, and others with a role in supporting health and well-being.

---

12 Reinersten, J et al. "Engaging Physicians in a Share Quality Agenda," 2007 Institute for Health Improvement.
13 Bernabeo, E and Homboe, E. "Patients, Providers, and Systems Need to Acquire a Specific Set of Competencies to Achieve Truly Patient Centered Care," Health Affairs, 32, no. 2 (2013); Legare, F and Witteman, H., "Shared Decision Making: Examining Key Elements and Barriers to Adoption into Routine Clinical Practice," Health Affairs, 32 No. 2 (2013).

► **Approaches and methods for reaching and engaging consumers at the policy and community patient engagement level are evolving and becoming more effective.**

Several grantees, such as MHMC and MCHO, are charged with explaining complex insurance and health cost information to consumers. They have developed innovative approaches to communicate information most effectively. MHMC's Pathway to Excellence public quality reporting system provides consumers substantial information on hospital and medical practice quality. It also depends on the involvement of providers and consumers to tailor the PTE reporting format. MHMC has learned over the years that active consumer engagement with the information available on the their websites requires that they carefully display and stage information for consumers in the same way retail vendors do. So, for example, if the consumer sees their provider has lower quality scores, they provide tools right there to direct them to other choices.

Translating quality rankings into something consumers can understand takes expertise and time. Portraying cost issues for consumers is particularly challenging. Consumers appear to automatically associate high quality with high cost. In portraying relative costs of different providers to consumers, MHMC initially used a dollar sign symbol, which reinforced this perception among consumers. In an effort to align their measures and encourage consumers to view "reasonable cost" as an indicator of good care, they replaced the dollar signs with "provides care at a reasonable cost" and used "Good", "Better", and "Best", the same measures used to describe quality, safety, and patient satisfaction.

Employers and health plans are increasingly promoting "Value Based Insurance Design" (VBID) as a tool to engage consumers and provide shared decision making.[14] This insurance design provides maximum coverage for evidence-based care, mid-coverage for preference-sensitive services with multiple potential treatments, and lowest coverage for supply-sensitive services where efficacy hasn't been established. MCHO's insurance products include VBID features which they recognized would be unfamiliar to many consumers who do not understand the basic terminology of insurance and feel inadequate navigating the insurance process. MCHO therefore created an "Health Insurance 101" presentation that staff can use to engage new plan members. As a core element of their outreach and education activities, MCHO also uses feedback from consumers to constantly re-craft their consumer communications and educational programs.

As a new member-led cooperative insurance company, MCHO is learning about the phases of engagement for their members, from recruitment to membership to governance, providing ongoing interactions with feedback from members on matters of plan design and policy. MCHO, which now has a consumer-led Board of Directors, demonstrates the movement from consultation to shared leadership on the continuum of engagement.

---

14 Value-based insurance design (VBID) is an approach that attempts to improve the quality of care by selectively encouraging or discouraging the use of specific health care services, based on their potential benefit to patients' health, relative to their cost.

Use of a Health Risk Assessment (HRA) has been an important tool for several grantees working on both the community and direct care levels of patient engagement.[15] In its first year MCHO has encouraged new members to complete an HRA through financial rewards, and relies in part on these assessments to inform the design of their plan benefits, such as chronic care management. During the first stage of its micro-wellness project MCDPH/Somerset Public Health used HRAs to help with health coaching and education for employees. Franklin and Mercy use an HRA with patients applying for charity care, as a tool to help patients understand their personal health risks and to support conversations about what strategies beyond clinical care will improve their health.

FINAL OBSERVATIONS

Since the launch of MeHAF's Advancing Payment Reform initiative in 2011, patient engagement has been an expectation of the foundation for all grantees. It has also become an increasingly important component of many of the funded projects as healthcare purchasers, providers and systems adopted new delivery system and payment models such as Patient Centered Primary Care and Accountable Care. So what has been learned from the projects funded under this initiative regarding the development, implementation, and impact of patient engagement strategies and initiatives? In this final section we share some of the higher level observations that may be relevant for future efforts to develop more patient/consumer-engagement within payment reform and a changing health system.

> ► **Patient engagement requires significant changes in professional and organizational norms and culture that are difficult to achieve and will likely take time.**

The experience of the 13 MeHAF-funded projects provides a glimpse of the scope and scale of the opportunities for, and challenges to, developing and implementing effective patient engagement strategies. As the comments of a number of grantees suggest, the power and strength of professional and organizational norms are currently stronger than the enthusiastic but more limited support of the idea by many in the health system. Advocacy on behalf of patient engagement is beginning however, and is likely to grow. Several grantees noted the current dearth of tools to measure patient engagement and its impact. While the paucity of measures and hard evidence of the impact of patient engagement on costs and other important outcomes may inhibit adoption or limit spread, research on the topic is expanding rapidly.

As noted in this brief, organization mission, senior leadership, and governance structures that support and reflect significant patient engagement are essential. While grantees report growing support among providers for patient engagement efforts, we cannot count on episodic provider exposure to a successful patient engagement experience to accelerate or sustain major transformation. Basic changes in provider culture need to begin with medical education, teaching modules and academic requirements for proficiency with team-based and patient-centered care. Graduate medical education needs to reinforce and train new providers in developing competency in shared decision making and working with community resources. Provider skills in patient engagement need to be rewarded as part of provider performance measures and compensation. Providers need to see patient engagement as having value relative to clinical outcomes and as directly related to their own professional satisfaction.

Whether health systems and leaders will "stay the course" and continue to promote and support professional and organizational change to expand patient engagement is anyone's guess. Like many things, the "tipping point" will be hard to discern until after it has been reached.

> ► **The strategies and tools for effecting the necessary changes to support greater patient engagement are limited.**

Noting the emerging nature of the patient engagement field and the lack of "best practice" resources, many grantees indicated that the quarterly grantee meetings that served as a learning collaborative were helpful for sharing and learning about useful techniques and methods to enhance patient engagement. For example, in addition to learning about the latest research on the Patient Activation Measure (PAM) from Judith Hibbard, grantees using the PAM had the opportunity to share their experiences with this tool with the other grantees. TAMC and EMHS found that PAM was most helpful in their guiding treatment and education of patients rather than as a predictive tool.

Learning collaboratives, such as those employed in this initiative and other health system transformation projects, are only one of the tools available to help organizations build and implement policies, systems, and programs to achieve greater patient engagement. Unfortunately much of current learning is driven by example and lacks a more systematized approach. What if there were a center for patient engagement in Maine that could review, evaluate and make available effective

---

15 Centers for Disease Control and Prevention define a HRA as "a systematic approach to collecting information from individuals that identifies risk factors, provides individualized feedback, and links the person with at least one intervention to promote health, sustain function and/or prevent disease."

patient engagement tools and strategies as well as provide support to organizations interested in using them? Organizations like Quality Counts and the Maine Health Management Coalition already function as quasi-resource centers to help their members and clients design and adopt best practices with regard to patient engagement. Beginning to build, disseminate, and support the patient engagement toolbox that organizations will need remains an important priority.

► **Changes in financial incentives for patients/ consumers and providers are likely to accelerate efforts to achieve greater patient engagement.**

The early experience with VBID, Pay for Performance, Shared Savings programs and other efforts to more fully engage providers and consumers suggests that financial incentives matter and can be significant drivers of change. As the health system more fully implements PCMH, ACO and other delivery and financing system models that contain such incentives, we are likely to see a corresponding acceleration of interest in and attention to patient engagement in the organization and delivery of healthcare. Additional external motivators for change could include making patient engagement central to accreditation and the development of ACO performance measures associated with patient engagement.

Investment in patient engagement is a challenging sell in today's more competitive and cost-focused hospital and healthcare fiscal environment. Without clear evidence of measurable health outcomes that are consistent with payer-driven quality measures or of control of costs, senior administrative and physician leaders may believe that engaging patients/consumers in decisions about their health and healthcare is the right thing to do, but the true strength of this belief will only be evident once research evidence establishes the "business case" for patient engagement. If and when that occurs we are likely to see a significant acceleration of efforts to more fully engage patients and consumers.

With limited evidence that fits the current construct of value in health care delivery, the visionary leader becomes critical for prioritizing patient and consumer engagement.

► **Efforts to promote patient engagement are heavily focused on healthcare. With a growing acknowledgement of the links between family, community, healthcare, and health, broader strategies and tools that apply to more than healthcare will be needed.**

As demonstrated by many of the grantees in this initiative, engagement with community organizations and partners is becoming a more central strategy as hospitals and health systems seek to address the underlying community and social circumstances and problems that contribute to health outcomes for their patients. Carman et al. posit that the effectiveness of patient engagement in system transformation efforts may be significantly enhanced by working across all three levels of patient engagement from clinical care to community and policy engagement.

As illustrated throughout this brief, many of the MeHAF grantees' projects worked on all levels of patient engagement and, in particular, focused on collaboration with community partners. While community social service organizations and health facilities have long worked together, particularly on behalf of vulnerable populations, the community is now an increasing part of the social-medical safety net.

What forms can "patient engagement" take in this broader community and policy context? First, as illustrated by the consumer advisory councils for the CCTs, consumer involvement in the design, implementation, and evaluation of community-level service integration, care management, and other initiatives ensures that voices other than healthcare and social services professionals are heard as critical questions are addressed around issues such as information sharing, communications, and approaches to locating and delivering services. This is particularly important in circumstances involving populations with complex needs, such as those with serious mental health problems or who come from different cultural or other backgrounds.

Patient/consumer engagement can also take the role of broader community and policy advocacy. Patient and consumer voices are critical as public and private organizations such as hospitals and health system or the MaineCare program pursue initiatives and/or policies aimed at health system transformation. Foundations such as MeHAF and non-profit health advocacy and delivery organizations health systems can play critical roles in creating the opportunities and mechanisms for meaningful patient or consumer involvement in public policy deliberations around health system transformation.

Appendix 1: MeHAF Project Descriptions

Cohort 1 – January 1, 2011 - December 31, 2012 (Four of five projects were renewed for two additional years, through December 31, 2014)

The Maine Health Management Coalition (MHMC) – MHMC is a non-profit organization of over 50 members (including public and private purchasers, hospitals, health plans, and doctors) that works to measure and report health care value, and help employers and employees use that information to make informed decisions. MeHAF's funding enabled MHMC to convene and support an Accountable Care Implementation (ACI) committee, through which it provided comprehensive support, tools and research to Maine health care organizations transforming their health systems into Accountable Care Organizations (ACOs). MHMC also provided payment modeling and data analysis expertise to support real-time decision-making by providers. The project addressed the state health plan's goal of advancing ACOs and strengthening the primary care infrastructure to reduce health care costs statewide.

MaineGeneral Health (MG) – is a non-profit healthcare system serving the Kennebec Valley area (via campuses in Augusta and Waterville, and other services). MeHAF's funding enabled MaineGeneral to include patients and families in transforming primary care as the system undertook a five-year pilot to redesign both clinical care and payment systems. MaineGeneral sought to develop models of patient and family engagement through patient advisory councils, and to include patients who were privately insured or uninsured to ensure breadth of perspective and experience. The project developed patient "peer navigators" – people who themselves are living with chronic conditions - who received training and support from MaineGeneral and several chronic disease prevention programs, enabling them to assist other patients in successful chronic disease self-management.

Medical Care Development, and the Greater Somerset Public Health Collaborative (MCDPH/Somerset)- both non-profit organizations focused on increasing the effectiveness of healthcare and public health systems - received MeHAF funding to develop a worksite wellness product specifically designed for rural micro- businesses, and for individuals as an add-on to current insurance coverage. Using incentives for participating businesses (mimicking tax credits or discounts for wellness plan participation as described in the Affordable Care Act), the project sought to demonstrate the business and employee value of worksite wellness plans. The later phase of the project sought to sustain and expand the successful employee wellness and insurance coverage efforts modeled with very small Somerset County businesses in partnership with Greater Somerset Public Health Collaborative (GSPHC) and communities participating in the Maine Development Foundation's Community Transformation Grant.

Prescription Policy Choices (PPC) (2011-2013) -a nonprofit educational and public policy organization focused on prescription drug policy – received MeHAF funding to work with health care providers, payers, and other stakeholder groups to ensure that the best science and data were used as health care providers, consumers and health plans decide how prescription drugs are prescribed, accessed and covered. Most broadly, the project sought to contain prescription drug costs; assist the uninsured and underinsured in obtaining reasonably priced medications; promote cost-effective alternatives to brand-name drugs; and ensure that prescription policies are addressed in new, affordable insurance coverage options.

Maine Quality Counts (QC) – an organization that "bring(s) together the people who give care, get care, and pay for care and provide leadership and tools to improve health and health care in Maine" – received MeHAF funding to develop a model structure for multi-disciplinary Community Care Teams (CCTs). CCTs are a component of Maine's Patient-Centered Medical Home pilot program, which seeks to reduce system costs and unnecessary care by connecting patients who have complex medical and social needs to comprehensive and coordinated services in their home communities. The grant supported the development of an explicit model for CCTs in Maine that includes defined standards for a sustainable organization which can be reimbursed by private and public payers, and that is (or can be) integrated with other payment and reform initiatives (including the statewide Patient-Centered Medical Home pilot.)

Cohort 2: January 1, 2012 - December 31, 2013

HealthInfoNet (HIN), Maine's nonprofit statewide health information exchange (HIE) has, over the course of its MeHAF funding, grown to serve close to all of Maine residents and hospitals. The HIE system links medical information from separate health care sites to create a single electronic patient health record, and allows authorized providers to see that record to support patient care.

With its MeHAF funding, HealthInfoNet expanded the clinical data collected by the exchange; transferred the data to a data warehouse environment; and demonstrated the integration of the statewide clinical data set with claims data. Key products of the grant included development of a data use policy and related procedures for data access and use; and planning for the use of clinical data in a Personal Health Record application.

Maine Primary Care Association (MPCA), and Maine Community Health Options (MCHO) – Maine's "CO-OP" Consumer Operated and Oriented Plan) – The Affordable Care Act provided the opportunity to develop new CO-OP insurance plans, offered through a state's insurance exchange/marketplace, and specifically intended for the small group and individual market. MeHAF funds enabled the MPCA to work with a cross-cutting team of partners to engage the small business community and the network of safety net providers in forming a Maine-based CO-OP, which went on to win federal start-up and solvency loans and became a separate nonprofit organization, MCHO. The benefits and attributes of the CO-OP plan were designed based on cost, quality and utilization data, and were designed to reduce the costs of insurance coverage for small businesses while leveraging the existing infrastructure of supports for healthier outcomes and improved overall population health. While MeHAF funds were directed towards the efforts to create MCHO, MPCA, as the association representing all Federally Qualified Health Centers in Maine, remained an active participant in the learning collaborative.

State of Maine, Department of Health and Human Services, MaineCare (Medicaid) program (MaineCare) – The state Medicaid program (MaineCare) received MeHAF funding to make progress on several facets of payment and delivery system reform, including developing and implementing a Health Homes program, and implementing a 'MaineCare Accountable Communities' program. Health Home services are now being delivered through a combination of enhanced primary care/PCMH services, linked with Community Care Teams to improve care and lower costs for the highest-need MaineCare members, and have begun to expand to include Behavioral Health Homes as well. The 'MaineCare Accountable Communities' program supports both practice and payment change needed for health systems, hospitals, and other provider groups to deliver more patient-centered, high-value care.

Cohort 3: January 1, 2013 - December 31, 2014

The Aroostook Medical Center (TAMC) – received MeHAF funding to develop a program to connect frequent users of Emergency Department services with primary care providers, ensuring that these patients have a primary care home, and reducing their use of the ED and Walk-in Care. TAMC worked to develop an engaged provider/patient/community partnership – a "Community Collaborative" – which has worked to inventory resources available in the community and help connect patients to services – both health and social – and better understand the practice redesign necessary to best serve these patients.

Eastern Maine Healthcare System (EMHS) - received MeHAF funding to examine whether Patient-Centered Medical Homes both reduce unnecessary health care utilization and increase patient satisfaction – particularly among those who are uninsured and underinsured. MeHAF funding enabled the project to: demonstrate (using a Return on Investment analysis) that engaging uninsured and underinsured patients within a PCMH will be sustainable within an ACO environment; explore how Patient Activation and a PCMH approach: a) improves the quality of care; b) improves the patient's experience, and c) reduces healthcare costs; and identify barriers to enrolling patients with chronic conditions in care coordination programs.

Franklin Community Health Network (Franklin) – used MeHAF funding to implement Franklin C.A.R.E.S. (Care Access, Resource, Education & Support), a program to serve financially disadvantaged individuals in need of healthcare services. Franklin began by examining data to better understand why their charity care expenses had risen dramatically from $1.5M to $6.7M in five years. After learning that the population was more diverse in its health and social needs than originally expected, the hospital worked to create programs and services that would best address the needs they had identified, including encouraging and facilitating patient engagement and insurance enrollment.

Maine Medical Education Trust (MMET) – received MeHAF funding to educate and provide legal and accounting tools to independent physician practices as they transitioned to work within an Accountable Care environment. With a focus on practices that serve MaineCare (Medicaid) and underinsured patients, MMET produced a Legal Toolkit explaining current payment reform initiatives, and key legal and strategic issues for physicians considering participation in them. MMET also surveyed physicians about their opinions on – and levels of understanding and participation in - payment reform; their perceptions and use of electronic health records.

MaineHealth – the state's largest integrated delivery system – used MeHAF funding to develop a new model of primary care reimbursement aligned with principles of Patient-Centered Medical Homes. Through financial analyses and real-world experimentation, MaineHealth sought to develop a scalable PCMH and compensation model that would remove barriers to delivering team-based care; would provide high quality, efficient, patient care, and would be financially sustainable under current and future payment arrangements..) These efforts have resulted in agreements with several MaineHealth member organizations to test delivering team based primary care under several reimbursement models, assessing impacts on clinical quality, outcomes and costs, and informing future efforts towards building a strong primary care system to achieve broad population health.

Mercy Hospital – received MeHAF funding to form the Mercy Medical Neighborhood Model - a collaboration with community partners and insurers that addresses the needs of the most costly charity care patients through an improved care and cost management program that mirrors Mercy's Accountable Care Organization practices. The elements of the effort include: financial counseling, medical necessity screening, utilization review, warm-hand-offs to a neighborhood-based team, and real-time emergency department care coordination. Key to success of the project have been new data sharing agreements between project partners enabling weekly and monthly reporting, and facilitating care management for the high utilizers.

A. Are you using any of the following patient/consumer engagement strategies:

1) Self-management tools

2) Shared decision-making

3) Assessing patient activation (e.g. Patient Activation Measure)

4) Patient experience surveys

5) Consumer education and outreach

6) Accessing health information (e.g. patient portals)

7) Communicating with providers about their care (e.g. secure messaging)

8) Patient reported health outcomes to inform care delivery

9) Other (specify)

B. Have you involved patients, consumers, or citizens as participants or advisors in any of the following:

1) Quality improvement committees or projects

2) Patient safety committees

3) Patient , consumer or citizen advisory groups

4) Governance committees

5) Other (specify)

Appendix 3: Patient Engagement Protocol

Intro: Remind grantee of their response to survey questions about patient engagement activities (completed at 8/7 grantee meeting). Explain that this follow-up interview is opportunity to hear more about their experiences with patient engagement. We are interested in casting a wide net on this subject and, therefore, would like to hear about patient engagement activity that may go beyond the MeHAF funded project.

Interview Questions and Probes (to be further revised based on survey results)

1) What have been the major lessons learned from your patient engagement efforts?

2) What are the chief barriers and facilitators in engaging and involving patients/consumers in 1)direct care, 2) organization design and governance, 3)community or public engagement, 4)policy making?

3) Have you provided any specific training for staff and providers in patient engagement approaches and tools? How would you describe providers' and staffs' attitude and beliefs about patient engagement?

4) How are you disseminating and using patient survey information? What have you learned from the surveys?

5) How would you describe your organization's culture and leadership regarding patient engagement efforts? Very supportive, supportive, neutral or negative?

6) What has been your experience in recruiting and engaging patients and consumer from vulnerable populations, such as the under or uninsured?   Lessons learned?