

Engaging Patients in Primary Care Quality Improvement Initiatives: Facilitators and Barriers

American Journal of Medical Quality
1–11
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1062860619842938
ajmq.sagepub.com
SAGE

Nancy Pandhi, MD, MPH, PhD¹, Nora Jacobson, PhD², Madison Crowder, BS¹, Andrew Quanbeck, PhD², Mollie Hass, BS², and Sarah Davis, JD²

Abstract

Health care transformation calls for patient engagement in quality improvement (PEQI), yet practice participation remains low. This pilot study of 8 primary care clinics at 7 statewide locations sought to determine the most effective strategies for disseminating a previously successful single-system PEQI intervention. Qualitative data were obtained through site visits, interviews, observations, and journaling. All material pertaining to barriers, recruitment/retention, and implementation was extracted, compared, and categorized. Five teams partially completed the intervention and 3 finished. These 3 teams did not ask for shorter trainings and were assigned a quality improvement (QI) coach. Multiple barriers to recruitment, implementation, and retention were noted at the organizational and clinic/team level, including turnover, shifting priorities, cross-level communication difficulties, lack of QI knowledge, and confusion between patient engagement and patient activation. These findings suggest that QI facilitation and dedicated time can help primary care teams identify and overcome barriers to PEQI.

Keywords

patient participation, patient care team, practice redesign, primary health care, quality improvement

Health reform efforts are increasingly mandating patient engagement as a critical component of primary care practice transformation that improves care quality.¹⁻³ Interventions that engage patients are desirable at all levels of the health care system—from direct care to organizational design and governance.⁴ For example, the Centers for Medicare & Medicaid Services (CMS) requires Accountable Care Organizations to include a Medicare beneficiary in shared governance.⁵ Additionally, CMS supports ambulatory care practices participating in its Transforming Clinical Practice Initiative in increasing patient engagement through providing technical assistance from a Support and Alignment Network.⁶

Despite these increasing expectations, practices report being unprepared to engage patients in quality improvement (QI) work. Consequently, the percentage of practices that meaningfully engage patients in QI efforts is low,^{7,8} with a major barrier identified as the lack of resources and knowledge about successful models to engage patients. From 2010 to 2014, the research team developed, implemented, and evaluated a patient engagement intervention across 26 primary care clinics at a single Midwestern academic health system.^{9,10} The 6-month intervention employed multiple concurrent implementation strategies, including a tool kit, in-person academic detailing from a patient engagement expert, and regular (weekly to monthly)

in-person QI coaching. Although this intervention successfully increased teams' involvement of patients in QI, consistent with other researchers,¹¹⁻¹³ the research team identified additional barriers, including competing demands, lack of leadership support, and limited time and resources to support this work.^{9,10} As such, in order to make scaling this intervention beyond the study academic health system feasible, the team recognized the need for the intervention to employ less resource-intensive strategies.

The research team conducted a multisite pilot study designed to provide information about the highest impact and most cost-effective combination of implementation strategies to be used in scaling up the intervention for engaging patients in primary care team-based QI work. This article reports the lessons learned from these efforts. The research team anticipates that these findings will be useful for those interested in patient involvement in system redesign and the implementation and evaluation of practice transformation efforts.

¹University of New Mexico, Albuquerque, NM

²University of Wisconsin-Madison, Madison, WI

Corresponding Author:

Nancy Pandhi, MD, MPH, PhD, Department of Family and Community Medicine, University of New Mexico, MSC 09 5040, 1 University of New Mexico, Albuquerque, NM 87131.
Email: NPandhi@salud.unm.edu

Methods

Context

This study was reviewed and granted an exemption by the Health Sciences Institutional Review Board at the University of Wisconsin-Madison. It was conducted by an academic research team consisting of a family physician/health service researcher, a patient engagement expert/health policy researcher, a qualitative and mixed methods expert researcher, a systems engineer specializing in implementation research, a QI coach, and a project manager/study coordinator. This team met bimonthly to discuss recruitment, implementation, data collection, and ongoing analyses.

The original 6-month intervention was embedded in a large-scale primary care redesign at a single organization.¹⁴ Teams were trained in cohorts that learned about QI using a microsystems approach.¹⁵ They met weekly, selected an improvement project, received training about engaging patients in these efforts, and received 6 months of QI coaching. For examining scalability in the pilot study, the research team adapted the preceding steps to focus QI training into a 30-minute session discussing Plan-Do-Check-Act cycles, using an applied example to demonstrate a practical tool such as process mapping. The in-person patient engagement session also was 30 minutes. Remote web-based technology and/or phone calls were employed for coaching after an initial in-person session.

Study Design and Intervention

The purpose of the pilot study was to assess the feasibility and preliminary effectiveness of different combinations of implementation strategies for promoting patient engagement in team-based QI work. The design called for recruitment of a total of 9 primary care teams from clinics across the state of Wisconsin that varied in geographical location, practice size, and patient population.

Clinics were assigned into 4 implementation strategies for this 6-month intervention in order to maximize variation and thereby increase the research team's knowledge about the highest impact and most cost-effective scale-up strategy. Clinics could receive (1) a patient engagement tool kit and accompanying web-based video recording from a patient engagement expert; (2) a tool kit plus a live session with the patient engagement expert; (3) a tool kit, patient engagement live session, and monthly sessions of in-person (month 1) and remote (months 2-6) QI coaching; and (4) a tool kit, recorded patient engagement session, and QI coaching. Additionally, all sites were offered a single in-person didactic session, "QI 101," in which the basics of QI theory and practice were reviewed.

Each clinic was asked to identify a team champion. This person was asked to serve as the primary contact with the research team and coach, as well as to encourage

her/his team's progress in patient engagement and improvement activities. Table 1 provides more details about the intervention within the 6-month time line.

Data Collection

The findings reported in this article were derived from the qualitative component of the data collection plan, as will be explained in detail. Data came from site visits, interviews, structured observations by the coach, and a research team journal containing detailed notes about the recruitment process and all interactions with study sites during the intervention period.

Site Visits and Interviews. Site visits were conducted at each participating clinic prior to the initiation of the assigned intervention. A team of investigators spent approximately 4 hours at each site. During this time they toured the clinic, met providers and staff, and conducted semistructured interviews with primary care team members (approximately 10-15 minutes) and QI administrators/clinic managers (approximately 1 hour). The semistructured interview was guided by the Consolidated Framework for Implementation Research.¹⁶ Questions sought specific information regarding previous QI and patient engagement experience, team communication processes and hierarchical structure, and perceived team, clinic, and organizational barriers and facilitators to participating in this intervention.

Follow-up interviews were conducted at those clinics that completed the intervention. These interviews focused on perceived facilitators and barriers to implementing the intervention, successes and failures when engaging patients in QI, overall opinions of the intervention, and plans to engage patients in QI in the future. Site visits were documented in summary reports. All interviews were audio recorded and transcribed verbatim.

Structured Observations. For sites assigned to the coaching component of the intervention, the coach recorded observations after each interaction using a standardized format that focused on clinics' progress in developing and implementing their projects, changes in outcomes, and next steps.

Research Journal. Investigators kept detailed notes on the recruitment process. All interactions with research sites, such as regular monthly check-ins during the intervention period, were documented. If sites withdrew, researchers conducted short exit interviews with health system administrators or team champions to ascertain and document the sites' reasons for withdrawal. All team meeting discussions were documented, along with ongoing lessons learned. A final wrap-up team meeting consisted of a focused discussion on lessons learned from recruitment and project implementation.

Table 1. A Time Line of Project Steps, Trainings/Tools, Actions, and Goals.

Time Line	Project Step	Training or Tool	Recommended Actions	Goals
Month 1	Introduction to QI and Begin a QI Project	QI 101 presentation	Learn basic QI	Understand basic QI approaches and tools
			Decide on a QI project	Identify an issue to improve
			Assemble an internal team to work on the project	Organize a team
		QI handout	Learn about the issue that needs improvement	Clarify current knowledge and understand root causes of problems
Month 2	Pre-Patient Engagement Planning and Continue Planning QI Project	Patient Engagement Introductory Presentation	Complete the Pre-Engagement Planning Worksheet	Understand basics of patient engagement and pre-engagement planning steps
		Patient Engagement in QI Tool Kit	Identify possible solution(s) for the issue	Prepare to engage patients in QI project(s) Select possible solution(s)
Month 3	Patient Engagement Planning and Start Engaging	Patient Engagement in QI Tool Kit	Complete the Patient Engagement Worksheet	Identify specific engagement opportunities for patients
			Recruit/invite patients to engage	Begin recruitment for engagement
Months 4 and 5	Engage Patients as You Continue Your QI Project	Patient Engagement in QI Tool Kit	Proceed through QI Steps Do-Check-Act	Adapt QI goals or project outcomes based on patients' inputs
			Include patients in appropriate QI steps	Improve systems, workflows, and care experiences
Month 6	Project Wrap-up and Next Steps	QI handout	Wrap-up or plan conclusion of QI project(s)	Complete QI project
		Patient Engagement in QI Tool Kit	Identify and discuss lessons learned, celebrate successes, and thank participating patients	Document any benefits or challenges of: project, patient contributions, and trainings
				Publicly and privately appreciate patients' contributions
			Talk with team about next steps after conclusion of formal project	Communicate next steps

Abbreviation: QI, quality improvement.

Data Analysis

Data analysis began during the bimonthly research team meetings, as investigators reviewed recent data (eg, site visit reports) and discussed both the progress of the pilot study and what was being learned about engaging patients in QI work. Many discussions focused on the barriers the team was encountering, and a decision was made to make these barriers one focus of the data analysis. Thus, for this article, case files (inclusive of all site visit reports, interview transcripts, and other notes) were constructed for each of the participating clinics/teams. The files were

reviewed and summary case studies developed. All material pertaining to barriers to recruitment/retention and implementation was extracted, explored, compared, and categorized. These categories were further refined through research team discussions.

Results

Recruitment

This pilot study encountered many challenges, the first of which was recruitment. Four recruitment strategies were

Table 2. Clinic Characteristics, Implementation Strategy, and Interviewees.

Clinic	Geographical Location	Size ^a	Primary Population	Implementation Strategy	Interviewees
A	Urban	Large	Commercially insured	<ul style="list-style-type: none"> • Patient engagement tool kit • Patient engagement expert recording 	<ul style="list-style-type: none"> • Clinic manager • Primary care physicians (×2) • Physician assistant (×2) • Certified medical assistant (×2) • Licensed practical nurse
B	Suburban	Small	Commercially insured	<ul style="list-style-type: none"> • Patient engagement tool kit • Live patient engagement session 	<ul style="list-style-type: none"> • Primary care physician • Physician assistant • Registered nurse (×2) • Licensed practical nurse (×2) • X-ray technician
C	Suburban	Large	Commercially insured	<ul style="list-style-type: none"> • Patient engagement tool kit • Live patient engagement session 	<ul style="list-style-type: none"> • Clinic manager • Receptionist manager • Primary care physicians (×2) • Registered nurse • Clinic coordinator • Certified medical assistant (×2) • Unit clerk
D	Urban	Medium	Publicly insured	<ul style="list-style-type: none"> • Patient engagement tool kit • Patient engagement expert recording • QI coach 	<ul style="list-style-type: none"> • Clinic manager • Ambulatory QI director • Primary care physician • Registered nurse • Licensed practical nurse
E	Rural	Small	Publicly insured	<ul style="list-style-type: none"> • Patient engagement tool kit • Live patient engagement session 	<ul style="list-style-type: none"> • Clinic manager • Receptionist/licensed practical nurse
F—2 teams	Rural	Large	Publicly insured	<ul style="list-style-type: none"> • Patient engagement tool kit • Live patient engagement session • QI coach 	<ul style="list-style-type: none"> • Clinic manager • QI administrative assistant • Nursing director • Primary care physician • Nurse practitioner • Registered nurse (×2) • Certified medical assistant (×2)
G	Urban	Large	Commercially insured	<ul style="list-style-type: none"> • Patient engagement tool kit • Live patient engagement session • QI coach 	<ul style="list-style-type: none"> • Clinic manager • Unit clerk supervisor • Primary care physician • Registered nurse • Certified medical assistant • Unit clerk

Abbreviation: QI, quality improvement.

^aSize based on practice population: Large >10 000; Medium 5000 to 9999; Small <5000.

employed. First, the research team engaged with a statewide quality improvement collaborative focused on public reporting of quality measures to send out an email to its listserv of QI administrators and organizational leaders at 35 health systems. Nine (26%) of these systems responded and set up an informational phone call. However, only 1 system out of 35 agreed to participate in the study, enrolling 3 of its clinics. This system had previously worked with the research team on another project. Reasons stated for nonparticipation included competing priorities from electronic health record updates,

leadership reorganization and transitions, concern over already overburdened primary care clinicians, and strategic foci on other primary care initiatives. Next, an email sent out via a regional Practice-Based Research Network did not generate any response (0%). Third, personalized emails were sent from a nonprofit QI consulting organization to 8 clinics. These yielded responses from 3 clinics (38%), all of which enrolled in the study. Last, an email to personal contacts at 2 systems in which the research team had prior relationships yielded 1 response and enrollment (50%).

Because of funding and time constraints, enrollment was stopped at 7 clinics, one of which enrolled 2 different teams (defined as several clinical support staff who worked with a single provider and her/his patient panel). Table 2 depicts the characteristics of these clinics, the implementation strategy to which they were assigned, and those who participated in initial site visit interviews.

Implementation and Retention

As shown in Table 3, clinics had different motivations for enrollment. Several clinics requested adaptations to the didactic portions of the intervention (eg, QI training, patient engagement training) to reduce training time so that it could fit into the structure of preexisting staff meetings. Table 3 also summarizes what happened at each site over the course of intervention. At the end, only 2 clinics (3 teams) completed the intervention. All of these teams did not shorten the time allotted for training, and were assigned a QI coach. For these teams, the didactic patient engagement component occurred either via a recorded session or live.

The barriers observed may be roughly categorized at the system level or clinic/team level. (Participants discussed their perceptions that there also might be patient-level barriers, such as a lack of interest in or aptitude for engagement among their patient populations, but these potential barriers were not observed directly.) At the system level these barriers included the following: (1) rapidly changing external environment with reorganizations and leadership turnover; (2) QI administrators were not decision makers for primary care participation; (3) research project values not aligned with the values of corporate health care; (4) shifting (or unclear/not well communicated) organizational priorities; and (5) research communication strategies not well aligned with hierarchical leadership structure, and information about the study from organizational decision makers was not passed along to the clinics. At the clinic/team level, barriers included the following: (1) staff turnover and other clinic-level personnel changes; (2) lack of prior team-based QI experience; (3) lack of tangible incentives for QI and patient engagement activities; (4) perception of QI as an administrative priority with little value for frontline staff; (5) lack of time and feeling too overworked to take on a new initiative; (6) interventions/expectations not clear to teams; and (7) confusion between patient engagement and patient activation and/or patient satisfaction.

As shown in Table 4 and illustrated by examples, multiple lessons were learned from both the recruitment and implementations stages of the project. These lessons highlight the difficulties in recruitment without prior established relationships. They also underscore the need

for the research team to establish ongoing dialogue with individuals across an organization at both the leadership and frontline levels. Reducing the time allocated for education, even though responsive to time and resource limitations, was unsuccessful. Implementation occurred most successfully when small teams were engaged, facilitating communication.

Discussion

In trying to spread a previously successful intervention for patient engagement in QI beyond 23 clinics affiliated with the study health system, numerous barriers to successful recruitment, implementation, and retention were encountered. Teams that completed the intervention required a resource-intensive combination of QI training, patient engagement resources, and regular contact with a QI coach. Failures of understanding and communication that cut across clinic/team and system levels hindered conduct of the research and implementation of patient engagement efforts. The research team found limited understanding of the concept of patient engagement among both system executives and clinic staff. Therefore, clear explanations about the purpose and expectations of this study were not conveyed by administration to frontline teams. In addition, shifting and unclear organizational priorities also created barriers. For example, in several clinics, teams' initial choices for a project focus were suddenly changed in order to more closely match a different, apparently new, priority. Finally, the current chaotic environment in primary care, characterized by severe constraints on time and other resources and by high rates of turnover and other personnel changes, proved to be the major barrier both to doing the research and to promoting engagement of patients in QI work.

Beyond these expected time and resource constraints,⁹⁻¹³ the research team discovered additional barriers at the clinic/team level. Consonant with a recent call for primary care practice staff and leaders to practice "regular quality improvement hygiene,"¹⁷ the team found the lack of frontline QI knowledge to be a barrier to engaging in practice transformation efforts while involving patients. At several clinics at the team's institution, QI work historically had been delegated to particular individual(s) with an administrative role, such as a practice or nurse manager. Specifically, frontline staff who made up the primary care teams lacked the knowledge, skills, resources, and incentives needed to conduct QI work. The QI 101 training was an attempt to address this lack, which was anticipated, but its utility proved to be somewhat limited, particularly without coaching to reinforce it.

Detailed understanding of the ways in which core components of an intervention are actually implemented

Table 3. Intervention Participation Motivations, Adaptations, Implementation Summary, and Outcomes by Clinic.

Clinic	Motivation for Study Participation	Implementation Adaptations	Case Summary	Outcome	Study Completion
Clinic A	Health system administrators selected this team to participate in the intervention because they hoped understanding patient engagement would help the team improve their low patient satisfaction scores.	20 minutes allotted for QI 101 training	Administrators reported that all team members had been trained in quality improvement QI (or that QI knowledge “comes naturally” as part of scientific training), but researchers found this not to be the case. Team members reported that the expectation they do QI was something being imposed on them from above, and that they were given no actual resources to pursue QI projects. Team members were overwhelmed with their patient care work and with frequent personnel changes. Team members generally equated patient engagement with patient satisfaction and with patient complaints.	The health system made the decision to withdraw all 3 of its clinics from the study before the team selected a project. Administrators reported that the decision had been based on the fact that the team was too busy and was confused about the aims and process of the study. In addition, the team was disappointed to have been assigned to a condition without coaching.	No
Clinic B	The clinic manager volunteered the clinic because of its emphasis on high patient satisfaction.	None	All team members emphasized the small size of the clinic and the closeness this engendered among staff members and between staff and patients. Previous QI experience was highly variable among team members. In general, team members valued QI because they saw it as a way to improve patient experience and health outcomes. When asked to talk about patient engagement, team members emphasized the high quality of their interpersonal relationships with patients.	At the time the health system withdrew from the study, the team had initiated a project focused on distance access to diabetes educators, begun analyzing the problem, and had a preliminary plan for patient engagement. The health system reported that they had considered allowing this clinic to remain in the study, but in the end decided that staffing issues would make continued participation too difficult.	No
Clinic C	This clinic’s team was selected by a clinic manager, who told the researchers, “I have lots of things I want to improve here.”	20 minutes allotted for QI 101 and 30 minutes for patient engagement training	Interviews with team members suggested there was a fair amount of tension between administrators and clinical staff and between different disciplines on the clinical teams. Most team members had little experience with QI and saw it as something that administrators wanted them to do, but that resulted in very little value because there was little focus or follow-through on results. Researchers’ questions about patient engagement prompted answers about the relationships between individual providers and patients. Team members emphasized that they had little time to do anything other than their clinical tasks.	At the time of drop out, the team had not yet chosen a project. At the exit interview, health system administrators reported that the team was confused and frustrated about the work they were supposed to be doing and lacked the time to continue to participate in the study.	No
Clinic D	Health system administrators chose this clinic because the physician was a QI champion and open to change.	A full hour was allocated to QI 101 to allow for questions, and several additional health system leaders and clinic staff members were invited and attended.	Clinic staff reported that their health system emphasized both QI and population health. QI activities appeared to be driven by individual physicians, who were monetarily incentivized to improve their metrics. In an environment described as “hierarchical,” staff engaged in QI activities only at the direction of the physician(s) with whom they worked. Most staff did not seem to have had prior training in or experience with QI. Questions about patient engagement prompted clinical staff to note “patients in this community aren’t used to being engaged,” which they attributed to their older, rural patients. In general, although clinic administrators were enthusiastic about patient engagement, which they defined as something like patient activation, members of the team seemed wary, equating it with providing a venue for patient complaints.	All parties liked the new process, and overall clinic lipid screening rates increased from 56% to 64.4%, with the rates of the participating physician team increasing from 62% to 69%. At the conclusion of the 6-month intervention, the team was figuring out how to scale up the new workflow to the entire clinic. They were optimistic about engaging patients in other situations in which there was disagreement among providers about the best way to institute a change.	Yes

(continued)

Table 3. (continued)

Clinic	Motivation for Study Participation	Implementation Adaptations	Case Summary	Outcome	Study Completion
Clinic E	The practice had recently participated in a successful QI project with a consultant and expressed interest in broadening their QI experience, with an eye toward improving patient health.	QI 101 and Patient Engagement training combined into a 1:1 conversation that occurred while the team member had breaks from other clinical duties.	<p>With the help of the coach, the team decided to focus their QI project on improving workflows around routine patient lab work (ie, lipid screening). They engaged patients by surveying them about their preferences for the timing of lab work vis-à-vis scheduled appointments. Based on the results of the survey and their analysis of the issue, clinic staff began asking patients to get their labs done before scheduled appointments. The team tracked screening rates, conducted further patient surveys to assess patient satisfaction with the new system, and also informally assessed provider satisfaction.</p> <p>This clinic was a 3-person operation, comprised of a physician and 2 staff members who each fulfilled multiple roles in the practice. In interviews, clinic staff made it clear that the physician would not be participating in the project, and also that he would limit what they could do as part of the project (eg, no patient surveys). Clinic staff described having close relationships with practice patients, but expressed skepticism that their patients would be willing or able to participate in QI work.</p>	The single staff member made efforts to figure out what needed to be done to encourage patients to complete advance directives, but encountered difficulties getting the information required. Ultimately, the practice decided to drop out of the study, citing recent personnel changes and a resulting lack of time to “[take] on extra projects.”	No
Clinic F	Two teams were selected by the health system administration to participate in this intervention based on these teams’ willingness to participate in QI.	None	<p>The “team,” which consisted of a single staff member, decided to focus the project on increasing the proportion of clinic patients with advance directives on file. The QI plan did not include a formal patient engagement component; instead, the team member viewed patient engagement as involving patients in making decisions about their own advance directives.</p> <p>Team members described a preventive care emphasis and a scheduling system that allowed them to have longer than average patient appointments. The clinic conducted frequent patient satisfaction surveys, but little was done with the results. Staff without administrative titles reported having little prior QI experience.</p>	<p>By the end of the 6-month intervention the teams had exceeded their stated benchmarks for the proportion of the providers’ patients with completed asthma plans—the team physician increased from 20% to 36% (goal for project: 30%) and the second team nurse practitioner increased from 16% to 51% (goal for project: 26%)—and were planning for how to improve numbers across the clinic. Clinic leadership expressed ongoing intent to consider patient engagement in future QI projects.</p>	Yes

(continued)

Table 3. (continued)

Clinic	Motivation for Study Participation	Implementation Adaptations	Case Summary	Outcome	Study Completion
Clinic G	A preexisting team that was working on issues related to the electronic health record in-basket was selected by the clinic manager.	None	<p>At the site visit, team members described a new no-show policy that was about to be implemented at the clinic, and expressed a desire to focus their project on the new policy. However, this was viewed as too negative, and by the time the coaching part of the intervention started, the focus had shifted to increasing the number of asthmatic patients with asthma plans in place. The teams began their efforts by running small tests of change on the workflows of 2 providers. Their plan for patient engagement, beyond a focus on completing asthma action plans as part of office visits, was to invite patients to a lunch and learn at which the asthma plans would be explained and patient feedback solicited. Despite inviting more than 100 patients to the lunch, no one showed up.</p> <p>Team members described many recent organizational and personnel changes and a sense of always being overworked and short on time. A single individual on the team had significant QI training and experience, but this was not shared by the rest of the group. Questions about patient engagement evoked statements about patients' customer service expectations, and team members had little vision for how patients might be engaged in QI work.</p>	<p>Before its second scheduled meeting with the coach, the clinic dropped out of the study. A subsequent conversation with the health system administration revealed that the new regional system administrator had not been aware of the project and did not want the clinic to participate. They cited the failure of the researchers to obtain proper permissions from the appropriate chain of command, concerns about sharing confidential corporate information with the researchers (conflicting the university with the competing health system affiliated with the university) and a belief that the focus of project did not reflect corporate priorities.</p>	No
			<p>During the site visit, team members spoke of their wish to focus their QI project on management of their electronic "in-basket" system. By the time the team had its initial meeting with the coach, however, they had shifted to a focus on vaccination rates.</p>		

Abbreviation: QI, quality improvement.

Table 4. Lessons Learned and Examples by Implementation Stage.

Implementation Stage	Lesson Learned	Example
Recruitment	Recruiting practice participants across multiple organizational settings takes a long time.	Recruitment for this project started in March 2016 and was not completed until October 2017. The research team aimed to recruit 9 practices yet only 7 practices were recruited.
	Recruitment was most successful when there was a preexisting relationship or via a warm handoff introduction from a known entity.	All participating clinics had a prior relationship with either the research team or the QI consulting organization.
	It is important to understand the relationship between practices and the recruitment partner.	Successful recruitment came from the organization that had a positive relationship with the clinics, and the clinics trusted the organization's recommendation to participate in the intervention.
	There is a need to understand motivations for participation at multiple levels (system leadership, clinic leadership, and grassroots team members).	The clinic teams that participated ranged in motivation. Some clinic teams were volunteered by the health system to become more patient-centered and to fix patient satisfaction scores and others teams thought it would make their day-to-day lives easier and would help with their workflow.
	Stakeholders at multiple levels need to clearly understand the intervention.	One clinic dropped out because of misalignment with overall health system goals. Other clinic teams dropped out because leadership did not understand the importance of QI and other outcomes.
Implementation	Adapting the intervention to meet clinics' time pressures was unsuccessful.	Clinics that dropped out of the intervention received 20 minutes of QI 101. One tried to fit education in while doing other clinical duties. These teams expressed confusion about the intervention and had difficulty choosing their own projects. Clinics that received the full trainings were better equipped to take on their projects.
	Teams found it challenging to identify their own QI projects.	Clinic teams were used to being told what outcomes or projects to work on from the overarching organization and did not have the processes or skills in place to choose their own projects.
	If teams did not understand the intervention, they had to backtrack and choose new projects.	Clinic teams did not understand the difference between patient activation and patient engagement. Projects were changed last minute to accommodate the patient engagement component.
	Academics and real-world practices had different beliefs about the importance and meaning of engaging patients in QI work.	Patient engagement was not an organizational goal and therefore teams did not have an expectation or motivation to include patient engagement in their QI projects.
	Academics trying to engage with systems that are potential competitors to their own health system may face suspicion. Smaller sized project teams with a clear champion were most successful.	The research team was asked to sign a nondisclosure agreement because their university owned a competing medical system. The 2 successful clinics formed workgroups of 3-4 people who met on a regular basis. They would then relay their progress back to the larger clinic team.

Abbreviation: QI, quality improvement.

in different contexts is critical for the scalability of practice transformation efforts. However, present study findings underscore the numerous barriers that can exist to conducting research in "real-world" primary care settings with unfamiliar contexts. At the system level, difficulties were encountered in engaging the correct level

of administrative decision makers by targeting the recruitment efforts to those involved in leading QI efforts. Through the failure of these efforts, the team discovered that actors at this level often lacked the authority to commit the organization to research participation and held an inflated sense of how attractive research

participation would be to primary care clinic staff. This combination led directly to many of the difficulties encountered when first recruiting sites and, later, retaining them. Additionally, something of a “two communities”¹⁸ culture clash was encountered; the research team failed to anticipate the perception of higher level system executives that research participation risked revelation of corporate secrets that might impart a competitive advantage to the health system affiliated with the team’s university. (While negotiating recent research partnerships between university-based investigators and corporate entities, the team has noted, anecdotally, that requests for researchers to sign nondisclosure agreements seem to be becoming more common.)

Limitations

The findings presented in this article are limited by the fact that they were derived from a single study conducted in a single state. Although these experiences seem to be consistent with those reported in the literature, the research team does not know how the primary care environment in Wisconsin may differ from those in other areas of country and thus cannot be sure how generalizable the conclusions may be. In addition, this work reflects the strengths and weaknesses inherent when investigators set out to evaluate an intervention of their own design. The team members who collected data were intimately familiar with the intervention, which likely enhanced the relevance of their interview questions and observations, but their investment in the patient engagement intervention also may have shaped the data. For example, research participants may have been reluctant to express negative opinions. Finally, the work of learning from a project that did not go according to plan requires a capacity for critical reflection on one’s own weaknesses. In such a situation, it is likely that, like all human beings, the investigators have some blind spots.

Conclusion

Although this study presents barriers to involving patients in primary care team-based QI discovered in the context of a research project, the research team believes that unless these barriers are addressed they likely will hinder widespread adoption of patient engagement as a standard element of primary care-based QI efforts. The findings support the importance of practice facilitation¹⁷ as only teams that received coaching were able to complete the intervention. In addition, education about the distinctions between patient engagement and patient activation or satisfaction and training in QI methods appears to be critical in order for practices to understand

the “why” and “how” of involving patients in practice transformation efforts.

Acknowledgments

The authors would like to thank the health care organizations and clinic teams that participated in this work, UW Health Quality, Safety, and Innovation, Zaher Karp, Natalie Wietfeldt, the Primary care Academics Transforming Health care (PATH) collaborative, and the Center for Patient Partnerships.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Institute for Clinical and Translational Research, which is supported by the Clinical and Translational Science Award program, the National Center for Advancing Translational Sciences (Grant 1UL1TR002373).

References

1. Family Medicine for America’s Health. Home page. <https://fmahealth.org/> Accessed September 28, 2018.
2. Fleming C. Health Policy Brief: Patient engagement. <https://www.healthaffairs.org/doi/10.1377/hblog20130215.028299/full/> Published February 15, 2013. Accessed September 28, 2018.
3. National Committee for Quality Assurance. 2017 PCMH standards and guidelines. <https://centralhealthcollaborative.files.wordpress.com/2017/06/2-pcmh-standards-and-guidelines-2017-edition-version-1.pdf> Accessed August 27, 2018.
4. 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;32:223-231.
5. 42 CFR 425.106—Shared Governance: Department of Health and Human Services. Baltimore, MD: Centers for Medicare and Medicaid Services; 2015.
6. Patient-Centered Primary Care Collaborative. Improving care through partnership with patients, families & communities. <https://www.pcpcc.org/tepi> Accessed August 18, 2018.
7. Han E, Hudson Scholle S, Morton S, Bechtel C, Kessler R. Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement. *Health Aff (Millwood)*. 2013;32:368-375.
8. Okun S, Schoenbaum SC, Andrews D, et al. *Patients and Health Care Teams Forging Effective Partnerships*. Washington, DC: National Academies Press; 2014.
9. Caplan W, Davis S, Kraft S, et al. Engaging patients at the front lines of primary care redesign: operational lessons for an effective program. *Jt Comm J Qual Patient Saf*. 2014;40:533-540.

10. Davis S, Berkson S, Gaines ME, et al. Implementation science workshop: engaging patients in team-based practice redesign—critical reflections on program design. *J Gen Intern Med.* 2016;31:688-695.
11. Sharma AE, Grumbach K. Engaging patients in primary care practice transformation: theory, evidence and practice. *Fam Pract.* 2017;34:262-267.
12. Willard-Grace R, Sharma AE, Parker C, Potter MB. Engaging patients as partners in practice improvement: a survey of community health centers. *J Sci Commun.* 2016;23:311-319.
13. Sharma AE, Willard-Grace R, Willis A, et al. "How can we talk about patient-centered care without patients at the table?" Lessons learned from patient advisory councils. *J Am Board Fam Med.* 2016;29:775-784.
14. Koslov S, Trowbridge E, Kamnetz S, Kraft S, Grossman J, Pandhi N. Across the divide: "Primary care departments working together to redesign care to achieve the Triple Aim." *Healthc (Amst.)*. 2016;4:200-206.
15. Nelson EC, Batalden PB, Huber TP, et al. Microsystems in health care: part 1. Learning from high-performing front-line clinical units. *Jt Comm J Qual Improv.* 2002;28:472-493.
16. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci.* 2009;4(1):50.
17. Bitton A. Finding a parsimonious path for primary care practice transformation. *Ann Fam Med.* 2018;16(suppl 1):S16-S19.
18. Caplan N. The two-communities theory and knowledge utilization. *Am Behav Sci.* 1979;22:459-470.