

Promoting Patient and Family Partnerships in Ambulatory Care Improvement: A Narrative Review and Focus Group Findings

Karin E. Johnson · Tracy M. Mroz · Marie Abraham · Marlaine Figueroa Gray ·
Mary Minniti · Wendy Nickel · Robert Reid · Jennifer Sweeney ·
Dominick L. Frosch · Debra L. Ness · Clarissa Hsu

Received: March 21, 2016 / Published online: June 28, 2016
© The Author(s) 2016. This article is published with open access at Springerlink.com

ABSTRACT

Introduction: Ambulatory practices that actively partner with patients and families in quality improvement (QI) report benefits such as better patient/family interactions with physicians and staff, and patient empowerment. However, creating effective patient/family partnerships for ambulatory care improvement is not yet routine. The objective of this paper is to provide practices

with concrete evidence about meaningfully involving patients and families in QI activities.

Methods: Review of literature published from 2000–2015 and a focus group conducted in 2014 with practice advisors.

Results: Thirty articles discussed 26 studies or examples of patient/family partnerships in ambulatory care QI. Patient and family partnership mechanisms included QI committees and advisory councils. Facilitators included process transparency, mechanisms for acting on patient/family input, and compensation. Challenges for practices included uncertainty about how best to involve patients and families in QI. Several studies found that patient/family partnership was a catalyst for improvement and reported

Enhanced content To view enhanced content for this article go to www.medengine.com/Redeem/EAD4F06021D7A862.

Electronic supplementary material The online version of this article (doi:[10.1007/s12325-016-0364-z](https://doi.org/10.1007/s12325-016-0364-z)) contains supplementary material, which is available to authorized users.

K. E. Johnson (✉) · M. Figueroa Gray · C. Hsu
Group Health Research Institute, Seattle, WA, USA
e-mail: karinjohnso@gmail.com

T. M. Mroz
University of Washington, Seattle, WA, USA

M. Abraham · M. Minniti
Institute for Patient- and Family-Centered Care,
Bethesda, MD, USA

W. Nickel
American College of Physicians, Philadelphia, PA,
USA

R. Reid
Trillium Health Partners, Mississauga, ON, Canada

J. Sweeney · D. L. Ness
National Partnership for Women and Families,
Washington, DC, USA

D. L. Frosch
PAMF Research Institute, Palo Alto, CA, USA

that partnerships resulted in process improvements. Focus group results were concordant.

Conclusion: This paper describes emergent mechanisms and processes that ambulatory care practices use to partner with patients and families in QI including outcomes, facilitators, and challenges.

Funding: Gordon and Betty Moore Foundation.

Keywords: Ambulatory care; Family engagement; Partnership; Patient engagement; Practice advisors; Quality improvement

INTRODUCTION

Improving patient and family centeredness is a key component of achieving the healthcare triple aim of improving population health and the care experience, and reducing costs of care [1]. The Affordable Care Act [2] emphasizes patient and family engagement, using the phrase “patient-centered” at least 40 times and supporting the transformation of primary care ambulatory practices to patient-centered medical homes (PCMHs). With the rapid spread of the PCMH model [3], ambulatory practices are seeking ways to redefine relationships with patients and families [4].

Carman et al. [47] developed a framework for better understanding definitions and mechanisms of patient engagement. In this framework, the “partnership” role is substantive, going beyond consultation and involvement and ranging from collaborative clinical visits (direct care level), to co-leading a quality improvement (QI) committee (organizational design and governance), and developing new policies and programs together with patients/families (policy making). In this paper, we focus on organizational design and

governance partnerships in ambulatory settings, specifically in QI.

QI in ambulatory care is typically conducted by a team or committee that reviews performance data, identifies improvement opportunities and undertakes QI initiatives [5]. Practices may also have advisory councils that make recommendations on better meeting patient/family needs. Council members share insights and experiences and collaborate with practice leaders and staff on specific QI efforts such as redesigning patient educational materials, creating patient portals for electronic health records or advising on health facility design [6]. We refer to patients and family members serving on QI or advisory committees or in other ambulatory care QI partnerships as “practice advisors.” Practice advisors have first-hand perspectives about patient/family needs and priorities. They provide a fresh view on the challenges that healthcare professionals face in healthcare redesign [7].

Analyses of practices undergoing PCMH transformation show that most obtain patient input, such as through surveys; however, few systematically involve patients and families as QI partners. Practices that actively engage practice advisors report benefits such as better patient/family interactions with physicians and staff, and patient empowerment [8]. However, creating effective patient/family partnerships for ambulatory care improvement is not yet routine.

Practices might hesitate to involve patients and families in improvement because evidence and practical guidance regarding best practices and expected outcomes are lacking [9]. The traditional paradigm of physician autonomy and control in medical decision-making means care is not structured to promote patient and family partnerships [10]. Patient/family QI

partnerships can be new territory for practices and patients.

Organizations such as the Institute for Patient- and Family-Centered Care (IPFCC), National Partnership for Women and Families (NPWF), and the Patient-Centered Primary Care Collaborative have been advocating for the inclusion of patients and families in ambulatory care QI. However, additional evidence and guidance are needed to support patient/family partnerships and disseminate their results so they become standard practice in ambulatory care settings.

To provide practices with concrete evidence about meaningfully involving patients and families in QI activities, this paper describes emergent mechanisms and processes that ambulatory care practices use to partner with patients and families in QI including outcomes, facilitators, and challenges. The focus on adult ambulatory care adds to the literature on partnerships in inpatient care and pediatric PCMHs [11].

METHODS

We conducted a targeted, narrative literature review to identify partnership activities, outcomes, barriers and challenges. We also elicited first-hand perspectives by conducting a focus group with ambulatory care practice advisors.

Targeted Narrative Review

The questions that the narrative review was designed to answer were: (1) what QI partnership activities exist at ambulatory care practices?; (2) what are the facilitators and challenges of such partnerships?; and (3) what are the outcomes? Article inclusion criteria were: explicit discussion of patient/family

partnership activities in practice design; focus on generalist adult ambulatory practice; and publication in English between January 1, 2000 and April 1, 2015. Exclusion criteria were a focus only on direct care (e.g., shared decision-making) or healthcare policy or one-time involvement/consultation. Articles were required to describe specific QI activities at one or more organizations. However, because one objective of the study was to identify existing partnership activities, no restrictions were placed on study design.

PubMed and Ebsco searches identified peer-reviewed articles. Initial search terms were based on team knowledge and key words from seminal articles and reports, with iterative refinement after team review. PubMed was searched for “patient partnership” and variants (collaboration, involvement, participation, engagement, and partner) and “patient advisory council” and variants (group, committee) in titles or abstracts. Ebsco was searched for “patient” and “engagement” in titles only based on initial PubMed results. “Engagement” was used instead of “partnership” because it covers a broader body of research. For both databases, we applied limiting terms for titles or abstracts to focus on ambulatory care (limiting terms: ambulatory care, primary care, family practice, outpatient and medical home) and organizational design and governance (limiting terms: practice, design, redesign, transformation, QI, quality initiative, and process improvement) versus direct care. We reviewed published and unpublished recommendations from our team and project advisors and citations from other articles.

Abstracts of all identified articles were reviewed. When abstracts were not available or lacked sufficient detail, full-text articles were reviewed. Two abstractors (TM, KJ), using

structured Excel abstraction forms that captured study design, setting, partnership structure and activities, facilitators and challenges, and results, reviewed two rounds of 50 articles each for training and inter-rater reliability. Concordance improved from the first test set ($\kappa = 0.38$; 95% confidence interval [CI] 0.02–0.75) to the second ($\kappa = 0.7$; 95% CI 0.41–0.98). Disagreements were discussed and resolved. Remaining abstracts were assessed by one reviewer, consulting with a second reviewer only in cases of doubt about articles meeting inclusion criteria.

Focus Group

A telephone-based focus group was conducted in 2014 with a purposive sample of highly experienced practice advisors recommended by IPFCC and NPWF, two organizations that frequently work closely with practice advisors. Participants were eligible if they spoke English, worked as an advisor for at least 6 months, and were not providers or staff members at the advised organization. Of 12 invitees, 10 patient advisors participated, with equal numbers of men and women, aged 35–74 years. Most advised practices that primarily served adults. The group was facilitated by two team members with training and experience in qualitative research and in-person and telephonic focus groups.

The focus group explored the experiences of current practice advisors. A guide (see the supplementary material) was designed to elicit insights from participants' experience, ideas about how ambulatory practices can prepare to work effectively with patient/family advisors in practice redesign and QI, and advice on encouraging and supporting patients and families in this role.

The focus group was recorded and transcribed. The team reviewed transcripts and discussed major themes. One author (KJ) coded the transcript in Atlas.ti based on a combination of a priori/template codes (drawing on focus group guide questions, e.g., on roles, practice advisor preparation, what went well, suggestions for improvement) and codes that emerged from the data [12]. The primary coder summarized major themes; another author (MM) read transcripts, reviewed the summary, and made adjustments after discussion.

Compliance with Ethics Guidelines

The Group Health human subjects review office determined that the procedures were exempt from IRB review. US regulations pertaining to human subjects research include provisions for exemption from Institutional Review Board review when research involves interviews that are deidentified [46]. Because the focus group occurred over the phone, no consent forms were collected. However, as noted in the focus group guide, participants were informed that participation was voluntary, quotes would be made anonymous, and that their insights will help “in sharing what really works to support patients and families in the role of advisors as improvement partners with health care professionals.” In addition, participants were given an opportunity to ask questions about the procedures before the focus group began.

RESULTS

Narrative Review

The PubMed search identified 810 articles on patient partnerships and the Ebsco search identified 139, with 6 duplicates. We identified

149 additional articles from partners' suggestions or other citations for a total of 1092 abstracts reviewed. Most exclusions were for a focus on clinical encounters (e.g., shared decision-making), input that did not meet the partnership criteria (e.g., completing a survey), or solely pediatric or inpatient settings.

Thirty articles discussed 26 studies or examples of patient/family partnerships in ambulatory care QI. Overlap between studies included, in particular, patient partnerships in PCMH demonstrations and the Robert Wood Johnson Foundation Aligning Forces for Quality initiatives, which were described in more than one paper. Most articles (17) were case studies (Table 1).

Most studies reported on patient partnerships in QI or advisory committees, although [13] described patients and families serving on clinical practice guideline committees and [14] reported on periodically hiring patients part-time to assist with peer-support activities, focus groups and wellness programs. Examples of specific activities by patients on standing committees included strategy development [15], staff interviews [16], input on improvement projects [17] and workflow development [18]. In three studies [19–21], practice improvement efforts were part of regional healthcare planning efforts and patient/family partners helped identify local priorities. Many programs incorporated patient/family partners into existing healthcare system functions, such as established committees and program material review. However, several designed new mechanisms specifically for partnership and co-design [19, 22–25].

Many articles reported that patient/family partnerships resulted in process improvements, including staff trainings [22, 26], service redesign [16, 17, 21, 27, 28], and patient

materials (e.g., for self-management or new patient orientation) [18, 29–31]. Several articles said patient/family involvement catalyzed practice improvement through “influential stories,” “different perspectives” [26] or “experiential knowledge” [32]. In addition to improving organizational processes, several articles said patient partnerships benefited patients directly by encouraging deeper communication with providers and motivating improvement and management of personal health [14, 15, 31]. No study reported changes in clinical outcomes associated with engaging patient partners, although three [17, 33, 34] reported correlation with improvements in quality-of-care process measures, including health coaching and care coordination.

Promoters and barriers for participating patients/families and practices are summarized in Table 2. For patients and families, facilitators included clearly defined processes, for example length of participation, confidentiality and privacy, training, ongoing communication and facilitation to ensure meaningful participation, and compensation. For practices, implementation facilitators included aligned values, practice cultures and policies. Previous experience or technical assistance on implementing patient partnerships was also cited as helpful.

Practice challenges can involve organizational and staff uncertainty about how to work with patients on QI and benefits of patient partnership. Practices may have concerns about burdening patients and ensuring representative voices. Challenges are compounded by competing demands in healthcare, leading to practices either not considering patient partnerships for QI or perceiving partnerships as work that cannot be accommodated because of resource constraints.

Table 1 Patient and family partnerships in ambulatory quality improvement, by study type

References	Setting	Patient/family partnership activities	Partnership outcomes
Randomized trials			
Boivin, Lehoux, Lacombe, et al. [19] /Boivin, Lehoux, Burgers, Grol [37]	Regional Health Authority in Canada	2-day deliberation meetings with patients prioritizing 37 options for community-level chronic care	“At the end of the trial, intervention sites’ priorities identified by patients with professionals were significantly different from control sites’ priorities identified by professionals alone”
Surveys			
Han et al. [8]	US PCMH practices	Suggestion box or other ad hoc method; patient and family surveys; qualitative input from individuals or small patient groups through interviews, group meetings, or clinic observations; ongoing participation in QI teams or patient/family advisory councils	More practices used partnership feedback to alert about potential problems vs. seeking input about solutions or improvements
Scholle et al. [9]	US PCMH practices with fewer than 5 physicians	Patients on QI committees or PCMH transformation teams in 15.5% of practices	No specific results reported
Qualitative studies			
Browne et al. [14]	Two primary care centers in poor urban Canadian neighborhoods serving marginalized populations	Patients periodically hired part-time to assist with peer-support activities, focus groups and wellness programs; and research (e.g. as interviewers)	“Participatory engagement of patients can take many forms and PHC organizations can play a role in providing a sense of meaningful belongingness, for example, by providing paid or volunteer opportunities including peer support programs”

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Caplan et al. [22]	University of Wisconsin primary care delivery system	Patient engagement training program developed during overall redesign efforts included coach and team member curricula, education and step-by-step how-to guides, tools, and templates. Created a 5-level framework for patient involvement, with level 5 being active partnership. Of 47 teams, 58 engaged patients (level-5 number not specified)	“Deepened our conviction that involving patients in the planning, development, and testing of clinical improvements is essential for improving quality and safety”
Carr et al. [26]	9 practices in 2 South-of-England trusts	Patients participated in eight half-day continuing medical education-type workshops over 9 months and facilitated project meetings about back-pain management for primary care teams	Viewed as catalyst for provider/staff behavior change, shifting perspective from medical to biopsychosocial model and increasing likelihood of motivating practice change compared to giving professionals information. Participation-influenced subthemes were “influential stories” and “different perspectives”
Luxford et al. [16]	8 US health care organizations: 5/8 ambulatory	Patient/family advisory committees and board-of-trustee representation, QI committees, employee interview panels and medical executive committees. Activities included involvement in organizational decisions (e.g., service redesign and staff-interview panels) and point-of-care engagement (e.g., partners in care; inclusion in handoffs; 24/7 point of access)	“Interviewees in five out of eight organizations cited the engagement of patients, families and carers as a critical strategy for promoting patient-centered care.” Acute inpatient facilities reported more extensive engagement

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Renedo et al. [15]	CLAHRC NWL	CLAHRC NWL envisioned patient participation in QI becoming normal practice across local healthcare context; funded, trained, and supported individual teams of 8–10 multidisciplinary frontline staff from National Health Service organizations conducting QI initiatives. Patients involved in strategy development and ongoing improvement events	Patients developed a sense of belonging and agency in interacting with healthcare professionals; from being passive recipients of healthcare to becoming active participants in service improvement ^a
Review articles			
Hubbard et al. [41]	Research and care planning efforts involving “people affected by cancer”	Multiple activities including “one-off involvement exercises” and “user involvement partnerships” in policy and planning	No specific empirical findings reported
Morrow et al. 2013 [32]	Mechanisms for partnership around chronic disease care	Advisory groups and patient-experience-based approaches to service design that link providers to community networks and support “perspective sharing” including patient input on agenda	“Experiential knowledge” shapes relevant questions and improvement approaches

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Case studies			
Angstman et al. [17]	Mayo Clinic, US	<p>“Patient advisory group” (defined as involved in long-term patient-centered processes) in place 5+ years. Twelve members are Mayo patients or parents interested in improving clinic healthcare, volunteered or selected by medical director; others are medical director and administrator. Meets quarterly</p> <p>Mission statement: “To establish a patient advocate forum to gain quality experiences, observations, and suggestions for improvement”</p> <p>Activities: review practice improvement project for depression care management; provide insights on scaling patient action group to entire Rochester, MN primary care practice</p>	Produced more patient-centered, personal-handoff process and associated provider scripting (e.g, from “someone will call you” to “the care manager is an RN who works with me”). Enrollment of patients diagnosed with depression into care management intervention was 96.5%
Baker et al. [29]	US CareSouth outpatient clinics	<p>Educational material design around body mass index after negative initial feedback regarding topic approach; revised pain assessment</p>	<p>“A strong collaborative engagement with the patient is likely necessary to achieve high reliability”</p>
Bitton et al. [27]	Hospital- and community-based primary care teaching practices affiliated with Harvard Medical School	<p>Clinic “transformation teams” encouraged to include patients as core members</p>	<p>“Trainees and patients can be agents of change, and their presence provides added motivation for academic faculty to create and support change”</p>

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Coulter and Elwyn [20]	UK policy efforts to involve public in healthcare processes	Community-health councils, proposed statutory patient forums and commission for patient and public involvement and health, patient advisory and liaison services in each trust, annual patient survey	No empirical findings reported
DiGioia et al. [23]	University of Pittsburgh Medical Center, US	6-step patient- and family-centered care methodology including using Codesign Toolkit and Improvement Team to close gaps between current and ideal care experiences	“Refocuses existing resources around the patient and family rather than fitting patients and families around the physician and system. It makes it possible to take any current state and move the care experience toward the ideal—as defined by patients and families”
Fontaine et al. [28]	Minnesota primary care practices	State PCMH certification standard development included patient-advocacy representatives; published standards include “continuous improvement process that included a quality-improvement committee with active patient recruitment and participation”	Patient’s positive experiences with PCMH increased practice leaders’ job satisfaction and trust in the process Process for using patients as PCMH advisors/getting input on PCMH changes from patient partners on change team all correlated significantly ($P \leq 0.01$) with practice system change (but not clinical outcomes) [33]
Karazivan et al. [24]	Direction of Collaboration and Patient Partnership at the University of Montreal: Implemented by two primary care teams as of 2014	Accompany clinical teams in implementation of care partnership continuous improvement approach	Results not yet available

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Loud et al. [30]; also described in Armstrong et al. [38]	Primary care for people with CKD in UK	Patient advisory group actively participated in QI planning including conference calls with participating practices; designed patient-outreach and support materials	Production of personal case studies and suggestions on explaining CKD from patient perspective to support healthcare professionals in explaining the project to patients. Production of patient-support tools (e.g. CKD information booklet for patients). Co-design and delivery of practitioner training on supporting people with CKD in self-management
Marshall and Nelson [13]	CF Foundation QI, launched in 2002	Patient/family advisory boards at CF care centers, patients/families on clinical practice guidelines committees. Provide input on improvement opportunities	“Enriched the improvement work and motivated the clinicians.” Patients and families received center-level access to outcome measures because “it became clear that it was the right thing to do and it would likely help us accelerate improvement”
Millenson et al. [34]	Mercy Clinic, US; also describes University of Pittsburgh Medical Center’s Patient- and Family-Centered Care [23]	Patient Advisory Workgroups on Quality at every clinic location. Patients comment on ongoing improvement plans. “Patient input sometimes contradicted doctor’s expectations; for example, physicians thought patients would be upset about depression screening, yet not a single patient objected”	Led to study of chronic care self-management showing “patients and clinicians were speaking 2 different languages.” Led to training health coaches in motivational interviewing directly related to patient wants and needs. Training program now institutionalized. Health coach program had financial benefits

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Minniti et al. [21]	Collaborative partnerships on the Oregon Medicaid population involving Oregon's legislature, the OHA, state MAC, Northwest Health Foundation, CareOregon, community groups, care providers	OHA task forces advanced patient-centered primary care homes to explore best practices in patient/family engagement. Individuals and families included as equal members. Developed Patient-Centered Primary Care institute, assembling technical experts, providers, staff, patient advisors, policymakers, academic centers, and other stakeholders to share practice transformation knowledge and resources. CACs required to work with Medicaid-coordinated care organization. CACs have 16–20 members representing a geographic area; at least 51% must be clients or family members receiving Medicaid services. CareOregon established a member advisory council	CareOregon's advisory council improved internal processes, helped expand dental coverage, and started partnerships in the broader health care community. Developed the Better Together guide to help CareOregon members prepare for clinic visits. Conversations with Oregon legislature influenced establishment of CACs and mandate to include Medicaid beneficiaries in the creation and ongoing operations of Coordinated Care Organizations
Morrison and Dearden [25]	CLAHRC programme for Sheffield. BOSOP	Team used participatory design methods so older patients and staff representatives could collaborate to drive improvements	Creation of design proposals that incorporated patient perspectives and experiences

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Roseman et al. [31]/Scanlon et al. [39]	Four US-based programs: one is Oregon's set of patient advisor programs, (Minniti, above); others are Humboldt county, replicated in South Central Pennsylvania; and Maine Aligning Forces for Quality pilot sites	<i>Humboldt:</i> Patient Partners recruited from patients who completed a local chronic disease self-management program and other sources. Periodic meetings are throughout the year with regular meetings of the full collaborative including providers and staff. Helped develop brochures and evaluate online portals; "serve as role models and working to improve care for all patients have prompted patient partners to become even more active in their own care" <i>PA Partners:</i> adapted Humboldt's program; focused on patient communication and self-management <i>Maine:</i> All pilot sites had patient advisors. Maine created a Patient Family Leadership Team in 2010 to provide support to pilot practices, since absorbed into other initiatives	<i>Humboldt:</i> "Having the Patient Partners at the table means the reason for this work is front and center for every discussion" <i>South Central PA:</i> Patients more active in their own care; sparking process changes that improve patient and staff satisfaction <i>Maine:</i> "Practice's patient advisory council has shifted providers' focus from 'what's the matter?' to 'what matters to you?'; helped identify practice matters of highest priority to patients; improved patient experience scores
Rubenstein et al. [40]	6 primary care practices in US Veterans Assessment and Improvement Laboratory for Patient-Centered Care	Patient representatives in Quality Councils and five topic-focused workgroups. Only one workgroup included a patient representative	No specific empirical findings reported

Table 1 continued

References	Setting	Patient/family partnership activities	Partnership outcomes
Stout and Weeg [18]	Cambridge Health Alliance, US	Process improvement team included 2 patients. Teams charged with spreading innovations between care teams and developing workflows	Input from frontline staff and patients accelerated development of workflow and tools accepted and used by care teams. "This allowed solutions to take hold more rapidly than in previous improvement efforts"

BOSOP better outpatient services for older people, *CAC* community advisory councils, *CF* cystic fibrosis, *CKD* chronic kidney disease, *CLAHRC* Collaborations for Leadership in Applied Health Research and Care, *MAC* Medicaid Advisory Committee, *NWL* Northwest London, *OHA* Oregon Health Authority, *PCMH* patient-centered medical home, *PHC* primary healthcare, *QI* quality improvement

Barriers for patients/families included lack of interest, time, training, and comfort with participating or training. Language and cultural differences and lack of trust in the medical system were a challenge for some [8].

Focus Group Findings

Of 10 patient/family practice advisors in the focus group, 8 advised in primary care settings and 2 in outpatient specialty care settings. Eight advised for at least 2–5 years and 2 for more than 5 years. All worked in urban settings: 4 on the West Coast, 2 on the East Coast and Midwest, and 1 each in the Rocky Mountain and Gulf Coast regions. Two were under 55 years, 3 were 55–64 years, and 5 were 65 years or older.

Becoming a practice advisor

Two participants became involved based on family caregiving. One had a child with a serious medical condition: "I got involved because it was so difficult to get access to good care and get quick access because I needed emergency services a lot, that's why they asked me to do it because I was always in the system." Several expressed desire and enthusiasm to serve the community and make the healthcare system work better for patients, for example:

"The reason I do these things is because I also receive Medicaid and I am so grateful to have that, that I want to do something to pay back."

Several participants were invited by their doctors to become practice advisors. Two were retired healthcare professionals. One said: "In my previous life I was a nurse practitioner [...] and then after I retired, I became a patient for 20 years so I feel like I have experiences on both sides of the table."

Table 2 Facilitators and challenges to patient/family partnerships in ambulatory quality improvement

Perspective	Facilitators	Challenges
Patient/family	<p>Clearly defined participation guidelines and expectations via role descriptions, commitment length, group purpose, directive, and/or mission statement [17, 30, 31]</p> <p>Confidentiality addressed, e.g. signed statement or agreement, ground-rules discussion [17, 26, 30]</p> <p>Preparatory or ongoing training to help patients actively participate [26, 41]</p> <p>Skilled facilitators/facilitation techniques [17, 19, 25, 26, 37]</p> <p>Appropriately sized groups to facilitate discussion (smaller = less intimidating) [17, 19]</p> <p>Regular communication to keep patients feeling involved, deepen relationships, and provide feedback on how practices used patient input [17, 22, 30, 41]</p> <p>Sessions provide opportunities for learning and fun for patients and providers [26]</p> <p>Compensation for participants (honorarium for time and/or reimbursement for travel expenses, meals, and child care) [14, 19, 26, 30, 31]</p>	<p>Language barriers and cultural differences leading to or along with skepticism and lack of trust in medical system may reduce patient likelihood of engagement in QI [8]</p> <p>Partnership activity descriptions may not appeal to patients (e.g. “program”) [8]</p> <p>Uncertainty about role and discomfort about speaking for other patients [32]</p> <p>Lack of training [40]</p> <p>Time for training and participation [40]</p>

Table 2 continued

Perspective	Facilitators	Challenges
Practice	<p>Practice values and culture support partnership, including:</p> <p>Viewing partnership as integral to practice design and quality assurance and improvement efforts; [8, 15, 18, 22, 23, 26, 34]</p> <p>Recognizing that patient presence motivates change [13, 31];</p> <p>Being comfortable with uncertainty of innovation and matching partnership activities with organizational readiness [22, 34];</p> <p>Getting active support from leadership and providers, including dedicated time and personnel, and [18, 22, 28, 31, 34, 41]</p> <p>Committing to translating findings into action [15]</p> <p>Policies that mandate or encourage partnership through financial incentives to practices or providers, reporting of key metrics, performance measures [8, 14, 20, 21, 23, 28, 31, 37]</p> <p>Implementation of partnership facilitated by:</p> <p>Prior experience with patient partnerships (e.g. patient advisory councils) [28];</p> <p>Technical assistance for practices [22, 31];</p> <p>Recruitment strategies that identify diverse potential participants and encourage involvement in partnership activities [19, 30, 31, 37], and</p> <p>Sessions that are enjoyable for patients and providers [26]</p>	<p>Uncertainty about how to work with patients on QI [9], how to respond to or act on feedback from patient partners [8], organizational capacity to deliver change [32], and sustainability of partnerships [40]</p> <p>Reactive nature of healthcare systems can hinder partnering with patients at planning and design stages [20]</p> <p>Perception that patient partnership time and costs are not feasible given competing priorities [19, 22, 26, 31, 34]</p> <p>Practices concerned about burdening patients with too much responsibility [20]</p> <p>Avoiding “tokenism,” recruiting diverse patients for a balanced viewpoint that represents the entire patient group [14, 20, 25, 31, 37, 41]</p> <p>Lack of evidence, best practices, or experience to convince skeptical providers and other stakeholders of patient engagement value [8, 9, 22, 31, 34]</p>

Commitment and Compensation

Most advisors were part of the practice's standing QI committee, which typically met monthly for 1–2 h and generally involved from 5 to 15 patient advisors, physicians and staff. One participant reported a system with three advisory councils, one focused on needs of Spanish-speaking patients. Some participated in activities beyond meetings: one worked directly with patients as a patient advocate; another was extensively involved, with activities from legislative testimony to self-management training; and another worked at the clinic level, on a system-wide council and co-chair participating in executive-level meetings with organization leaders. One advisor reported compensation for gas and committee participation time. None received honoraria.

Infrastructure and Support

The committees in which the practice advisors participated were often coordinated by a staff responsible for meeting and communication logistics, sometimes in a dedicated role and sometimes within a larger job. Staff oriented new advisors and supported them between meetings. A staff liaison to follow-up on meeting items was mentioned as important.

Three advisors received training for their role. One received the same orientation as the organization's employees. One received an individual orientation. Another received ongoing training through conferences and other activities. No other participants reported training. One explained, "We kind of just went by the seat of our pants because all of us have been patients there for many years."

Advisor Roles and Activities

Patient/family advisor roles included reviewing and providing feedback on written materials for patients (e.g., newsletters, orientation packets) and contributing to the organization and flow of patient visits from a patient-experience perspective. For example:

We focus on improving the patient experience through quality improvement. We focus on educating patients on preventive care and services, and we create in subcommittees with [practice] staff and their health education department, posters, brochures. We've done a video on the medical home. And then also I serve on the neighborhood clinic.[...] I've observed the lobby, rooming and met with various physicians in the different teams, just observing and asking questions, and from that we've created projects and they've made tweaks in the way they do their processes in the clinic level.

We actually gave the critical considerations in selection of the [patient electronic health information] portal. So we didn't decide which portal they were going to use, but we said these are critical questions that should be asked to the developer of the portal about how to comply with the variety of needs.

Other described eliciting patient feedback through comment boxes or one-on-one conversations, advising on executive-level agendas to ensure consideration of patient perspectives, and helping with the practice's community engagement efforts, including Medicare enrollment and food banks. At one clinic, patient advisors helped develop grants for new initiatives, for example a proposal to

acquire clinic furniture for patients and families.

Practice Advisor Perspectives on Benefits and Challenges

Patient advisors indicated that they were involved because their efforts resulted in tangible differences in patients' care experiences. For example:

[I value being] in a position to address issues with staff and physicians and to serve with other council members so that we can make contributions in this area. We've seen quite a few changes that have come out of our participation in this council.

Participants generally described positive experiences working with clinicians and staff with opportunities for bidirectional learning.

Staff, physicians and the people that have been chosen for our council by the doctors really do seem to care and there is a core group that attends regularly and it does provide us with consistency.

So the doctor came and said "all right, how can we assure these patients got their follow-up instructions, got their medications, know how to take their medications, know that we have an appointment, for just even the doctors to know that the patient has been in the hospital and was discharged from the hospital?" So we worked on that, and I think it was very helpful for the staff to bring issues to us that they felt we could help them with.

Challenges and suggestions regarding working with clinicians and staff included the healthcare system's concern about

confidentiality. Some participants said clinicians were not sufficiently aware of or did not spend enough time with patient advisory councils; however, the discussion focused on inviting clinicians and staff to join meetings and opportunities for relationship building. Patient/family partnerships can mean shifting organizational culture, which can be challenging.

I think sometimes the providers were hesitant to talk about some of the things within the clinic.

The materials coming out of the offices are me-oriented. For example we'll have a publication that says "we now have such and such service" and I'm trying to get the mindset changed so it comes from the patient's point of view, and it's a little struggle.

The participants discussed getting broader input from a range of patients and families. Recommendations included incentives and publicity around input opportunities and committee term limits so new people can join.

We don't have a direct way for patients, if they so choose, to send concerns to the advisory board.

I think everybody deals with how to recruit more people. One meeting we talked about term limits, that got a rise from some of our senior members, but basically that is tied into recruitment. [...] We're consistently seeking new capable people to join the advisory boards.

DISCUSSION

This paper summarizes mechanisms for patient and family partnerships in ambulatory care QI,

with outcomes, facilitators and challenges. In addition to involvement in standing QI committees and advisory councils, we identified efforts to include practice advisors in clinical guideline review committees, system transformation initiatives, and innovative practice redesign.

Facilitators for partnering with patients and families for QI in ambulatory settings included, for patients, identifying a shared purpose and clearly defined guidelines for participation. Providing orientation can ensure that advisors feel involved and valued. Addressing confidentiality and ground rules with practice advisors supports open and productive discussion and trusted communication. For practices, facilitators were clearly articulated support and commitment from leadership, including dedicated time and personnel, and comfort with uncertainty and innovation. Partnership implementation can be facilitated through technical assistance, policies that support partnership, and recruitment strategies that identify appropriate participants.

Challenges for patients and families included the time for training and participation. Patients indicated discomfort with speaking for other patients and uncertainty about their role. For practices, barriers included perceptions that partnership time and costs were not feasible given competing priorities. Practices sometimes questioned the value of patient engagement given lack of evidence and experience. Uncertainty about how to work with patients and families in QI and how to act on feedback were also challenges.

Our results offer insights on partnership benefits to practices. Articles and focus group participants reported that partnerships improved processes. Preliminary findings from inpatient experiences support that including patient/family advisors in improvement

initiatives may improve processes and potentially even improve quality and safety and reducing costs [35]. With providers under increasing demands, patient/family partnerships might enhance clinician job satisfaction. For example, in an Aligning Forces for Quality initiative, one practitioner remarked, “Engaging patients is the hardest core expectation but the most fun” [31]. Partnerships are also meaningful for patients, for example providing a sense of “meaningful belongingness” [14]. Thus, although some practices may perceive patient partnerships as prohibitively time and cost intensive, partnership benefits may offset their required time and resources by guiding practice decisions to be responsive to patient/family needs and priorities.

Coulter [48] noted that evidence to guide patient engagement is widely dispersed among multiple disciplines and journals. We synthesized and expanded previous publications on the scope, facilitators and challenges of patient partnerships in ambulatory care. The findings—including how the perspective and experiences of patient and families can catalyze improvement, and the need for guidance and training for practices and practice advisors alike—are consistent with previous analyses from inpatient and pediatric PCMH settings [11, 42–45]. However, the present analysis identifies partnership activities, barriers and challenges that are specific to the ambulatory care setting, for example related to practices’ workflow and incentive structures. Strengths of this study include incorporating expertise from organizations and individuals experienced in patient/family QI partnerships. This expertise is reflected in published and unpublished materials included in the narrative review, as well as focus group findings. Several identified resources are shown in Table 3.

Table 3 Sample resources for patient and family partnership in ambulatory care quality improvement

A Roadmap for Patient and Family Engagement in Healthcare Practice and Research

www.patientfamilyengagement.org

Aligning Forces for Quality

forces4quality.org

Institute for Patient- and Family-Centered Care

www.ipfcc.org/advance/topics/primary-care.html

Patient Engagement in Redesigning Care Toolkit

www.hipxchange.org/patientengagement

Patient-Centered Primary Care Collaborative Patients, Families, and Consumers Center

www.pcpcc.org/patients-families-consumers

Team Up for Health

www.teamupforhealth.org

Limitations of this study include a small focus group sample that may not be representative. Literature review results include learnings from other countries, which might not apply to the United States. Our conclusions about patient and family partnership outcomes are limited given that we identified only one randomized trial about policy and practice in Canada; however, findings from this trial and other higher quality studies were similar to findings from case studies. In addition, the concordance of findings between the focus group and the narrative review helps support the validity of the research from each method. Ambulatory practices are increasingly inviting patients and families to participate in QI efforts. These efforts are enabled by the rapidly evolving healthcare landscape that incentivizes patient and family engagement in care and improvement, and new techniques to build capacity for patient partnerships in QI, including experience-based design [36]. We

encourage the continued sharing of outcomes and best practices for creating and sustaining these important partnerships.

ACKNOWLEDGMENTS

We are grateful to the focus group participants for their work as practice advisors and for the time they took to share their insights with us. We are also grateful to Barb Forss for her insights as a patient advisor and review of the manuscript. This project was funded by the Gordon and Betty Moore Foundation. All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this manuscript, take responsibility for the integrity of the work as a whole, and have given final approval for the version to be published.

Disclosures. The authors are employed by organizations focused on healthcare improvement; however, Karin E. Johnson, Tracy M. Mroz, Marie Abraham, Marlaine Figueroa Gray, Mary Minniti, Wendy Nickel, Robert Reid, Jennifer Sweeney, Dominick L. Frosch, Debra L. Ness, and Clarissa Hsu have declared no specific financial conflict of interest.

Compliance with Ethics Guidelines. The Group Health human subjects review office determined that the procedures were exempt from IRB review. US regulations pertaining to human subjects research include provisions for exemption from Institutional Review Board review when research involves interviews that are deidentified [46]. Because the focus group occurred over the phone, no consent forms were collected. However, as noted in the focus group guide, participants were informed

that participation was voluntary, quotes would be made anonymous, and that their insights will help “in sharing what really works to support patients and families in the role of advisors as improvement partners with health care professionals.” In addition, participants were given an opportunity to ask questions about the procedures before the focus group began.

Open Access. This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits any noncommercial use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

REFERENCES

- Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff*. 2008;27(3):759–69.
- Patient Protection and Affordable Care Act, 42 USC § 18001, (2010).
- Bitton A, Martin C, Landon BE. A nationwide survey of patient centered medical home demonstration projects. *J Gen Intern Med*. 2010;25(6):584–92.
- Nutting PA, Crabtree BF, Miller WL, Stange KC, Stewart E, Jaen C. Transforming physician practices to patient-centered medical homes: lessons from the national demonstration project. *Health Aff (Millwood)*. 2011;30(3):439–45.
- Knox L, Brach C. Practice facilitation handbook module 14. Creating quality improvement teams and QI plans. Rockville: Agency for Healthcare Research and Quality. 2013.
- Conway J, Johnson B, Edgman-Levitan S, Schlucter DF, Sodomka P, Simmons L. Partnering with patients and families to design a patient- and family-centered health care system: a roadmap for the future. Bethesda: Institute for Family-Centered Care (In collaboration with Institute for Healthcare Improvement). 2006.
- Research Health, Trust Educational. Partnering to improve quality and safety: a framework for workign with patient and family advisors. Chicago: Health Res Educ Trust; 2015.
- 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(2):368–375.
- Scholle SH, Asche SE, Morton S, Solberg LI, Tirodkar MA, Jaen CR. Support and strategies for change among small patient-centered medical home practices. *Ann Fam Med*. 2013;11(Suppl 1):S6–13.
- Anderson RM, Funnell MM. Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. *Patient Educ Couns*. 2005;57(2):153–7.
- Scholle SH, Torda P, Peikes D, Han E, Genevro J. Engaging patients and families in the medical home (Prepared by Mathematica Policy Research under Contract No. HHS290200900019I TO2.) AHRQ Publication No. 10-0083-EF. Rockville: Agency for Healthcare Research and Quality; 2010.
- King N. Doing template analysis. In: Symon G, Cassel C (eds). *Qualitative organizational research: core methods and current challenges*. London: Sage Publications, Inc.; 2012.
- Marshall BC, Nelson EC. Accelerating implementation of biomedical research advances: critical elements of a successful 10 year cystic fibrosis foundation healthcare delivery improvement initiative. *BMJ Qual Saf*. 2014;23(Suppl 1):i95–103.
- Browne AJ, Varcoe CM, Wong ST, Smye VL, Lavoie J, Littlejohn D, et al. Closing the health equity gap: evidence-based strategies for primary health care organizations. *Int J Equity Health*. 2012;11:59.
- Renedo A, Marston C, Spyridonidis D, Barlow J. Patient and public involvement in healthcare quality improvement: how organizations can help patients and professionals to collaborate. *Public Manag Rev*. 2015;17(1):17–34.
- Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care: J Int Soc Qual Health Care/ISQua*. 2011;23(5):510–5.

17. Angstman KB, Bender RO, Bruce SM. Patient advisory groups in practice improvement: sample case presentation with a discussion of best practices. *J Ambul Care Manag.* 2009;32(4):328–32.
18. Stout S, Weeg S. The practice perspective on transformation: experience and learning from the frontlines. *Med Care.* 2014;52(11 Suppl 4):S23–5.
19. Boivin A, Lehoux P, Lacombe R, Burgers J, Grol R. Involving patients in setting priorities for healthcare improvement: a cluster randomized trial. *Implement Sci: IS.* 2014;9:24.
20. Coulter A, Elwyn G. What do patients want from high-quality general practice and how do we involve them in improvement? *Br J Gen Pract: J Royal Coll Gen Pract.* 2002;52(Suppl):S22–6.
21. Minniti M, Abraham M, Johnson B. Individual and family engagement in the medicaid population: emerging best practices and recommendations. New Jersey: Robert Wood Johnson Foundation; 2014.
22. Caplan W, Davis S, Kraft S, Berkson S, Gaines ME, Schwab W, 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(12):533–40.
23. DiGioia AM 3rd, Fann MN, Lou F, Greenhouse PK. Integrating patient- and family-centered care with health policy: four proposed policy approaches. *Qual Manag Health Care.* 2013;22(2):137–45.
24. Karazivan P, Dumez V, Flora L, Pomey MP, Del Grande C, Ghadiri DP, et al. The patient-as-partner approach in health care: a conceptual framework for a necessary transition. *Acad Med: J Assoc Am Med Coll.* 2015;90(4):437–41.
25. Morrison C, Dearden A. Beyond tokenistic participation: using representational artefacts to enable meaningful public participation in health service design. *Health Policy.* 2013;112(3):179–86.
26. Carr EC, Worswick L, Wilcock PM, Campion-Smith C, Hettinga D. Improving services for back pain: putting the patient at the centre of interprofessional education. *Qual Prim Care.* 2012;20(5):345–53.
27. Bitton A, Ellner A, Pabo E, Stout S, Sugarman JR, Sevin C, et al. The Harvard Medical School Academic Innovations Collaborative: transforming primary care practice and education. *Acad Med: J Assoc Am Med Coll.* 2014;89(9):1239–44.
28. Fontaine P, Whitebird R, Solberg LI, Tillema J, Smithson A, Crabtree BF. Minnesota's early experience with medical home implementation: viewpoints from the front lines. *J Gen Intern Med.* 2014;30(7):899–906.
29. Baker NJ, Crowe VL, Lewis A. Making patient-centered care reliable. *J Ambul Care Manag.* 2009;32(1):8–15.
30. Loud F, Jain N, Thomas N. How to develop a patient and carer advisory group in a quality improvement study. *J Ren Care.* 2013;39(Suppl 2):2–9.
31. Roseman D, Osborne-Stafsnes J, Amy CH, Boslaugh S, Slate-Miller K. Early lessons from four 'aligning forces for quality' communities bolster the case for patient-centered care. *Health Aff (Millwood).* 2013;32(2):232–41.
32. Morrow E, Cotterell P, Robert G, Grocott P, Ross F. Mechanisms can help to use patients' experiences of chronic disease in research and practice: an interpretive synthesis. *J Clin Epidemiol.* 2013;66(8):856–64.
33. Solberg LI, Crain AL, Tillema JO, Fontaine PL, Whitebird RR, Flottemesch TJ, et al. Challenges of medical home transformation reported by 118 patient-centered medical home (PCMH) leaders. *J Am Board Fam Med: JABFM.* 2014;27(4):449–57.
34. Millenson ML, DiGioia AM 3rd, Greenhouse PK, Swieskowski D. Turning patient-centeredness from ideal to real: lessons from 2 success stories. *J Ambul Care Manag.* 2013;36(4):319–34.
35. Lewis B. PFACs: where's the money? The financial impact on hospitals. Washington: The Beryl Institute; 2014.
36. Boyd H, McKernon S, Mullin B, Old A. Improving healthcare through the use of co-design. *NZ Med J.* 2012;125(1357):76–87.
37. Boivin A, Lehoux P, Burgers J, Grol R. What are the key ingredients for effective public involvement in health care improvement and policy decisions? A randomized trial process evaluation. *Milbank Q.* 2014;92(2):319–50.
38. Armstrong N, Herbert G, Aveling EL, Dixon-Woods M, Martin G. Optimizing patient involvement in quality improvement. *Health Expect: Int J Public Particip Health Care Health Policy.* 2013;16(3):e36–47.
39. Scanlon DP, Beich J, Alexander JA, Christianson JB, Hasnain-Wynia R, McHugh MC, et al. The aligning forces for quality initiative: background and evolution from 2005 to 2012. *Am J Manag Care.* 2012;18(6 Suppl):s115–25.
40. Rubenstein LV, Stockdale SE, Sapir N, Altman L, Dresselhaus T, Salem-Schatz S, et al. A

- patient-centered primary care practice approach using evidence-based quality improvement: rationale, methods, and early assessment of implementation. *J Gen Intern Med.* 2014;29(Suppl 2):S589–97.
41. Hubbard G, Kidd L, Donaghy E, McDonald C, Kearney N. A review of literature about involving people affected by cancer in research, policy and planning and practice. *Patient Educ Couns.* 2007;65(1):21–33.
 42. Britto MT, Vockell AB, Munafo JK, Schoettker PJ, Wimberg JA, Pruett R, et al. Improving outcomes for underserved adolescents with asthma. *Pediatrics.* 2014;133(2):e418–25.
 43. Khan A, Furtak SL, Melvin P, Robers JE, Schuster MA, Landrigan CP. Patient-reported errors and adverse events in hospitalized children. *JAMA Pediatr.* 2016;170(4):e154608.
 44. Koutantji M, Davis R, Vincent CA, Coulter A. The patient's role in patient safety: engaging patients, their representatives, and health professionals. *Clin Risk.* 2005;11(3):99–104.
 45. Morrise L, Stevens KJ. Training patient and family storytellers and patient and family faculty. *Perm J.* 2013;17(3):e142–145 (Summer).
 46. US Department of Health and Human Services, Office for Human Research Protections. Human subject regulations decision charts. Chart 2: is the human subjects research eligible for exemption? <http://www.hhs.gov/ohrp/regulations-and-policy/decisiontrees/index.html#c2>. Accessed 1 June 2016.
 47. Carman K, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff.* 2013;32:223–231.
 48. Coulter A. Patient engagement—what works? *J Ambul Care Manag.* 2012;35(2):80–9.