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Title

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Permalink

<https://escholarship.org/uc/item/649823x6>

Journal

Family Practice, 34(3)

ISSN

0263-2136

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Publication Date

2017-06-01

DOI

10.1093/fampra/cmw128

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Peer reviewed

Review

Engaging patients in primary care practice transformation: theory, evidence and practice

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Abstract

Patient engagement is a fundamental strategy for achieving patient centred care and is receiving increasing attention in primary care reform efforts such as the patient-centred medical home and related care models. Much of the prior published theory and evidence supporting patient engagement has focused on improving engagement in individual care. Much less is understood about engaging patients as partners in practice improvement at the primary care clinic or practice level. We review the historical and policy context for the growing interest in the USA and UK in patient engagement at the primary care practice level, highlight findings from systematic reviews of the research evidence on practice-level patient engagement and discuss practical considerations for implementing patient engagement. We conclude that while there are persuasive ethical and social justice reasons for empowering patient involvement in practice improvement at the clinic level, research conducted to date in primary care provides suggestive but not yet resounding evidence in support of the instrumental triple aim benefit of practice-level patient engagement. We propose a research agenda to better understand the process and outcomes of practice-level patient engagement and its potential advantages to both the practice and the patients and communities served. Better evidence as well as resources to support and incentivize effective and feasible engagement methods are needed to catalyse greater diffusion of practice-level patient engagement in primary care practices.

Key words: Patient-centred care, patient-centred medical home, patient engagement, patient and public involvement.

Health systems across the world are stressing the importance of patient-centred care. The WHO global strategy on ‘people-centred’ services calls on health systems to engage and empower individuals, families and communities as more active participants (1). This resolution marks a major prioritization of not just global primary care infrastructure but also the involvement of patients and communities in health care planning and governance. The Institute of Medicine includes patient centredness as one of the six essential components of quality care (2). Patient centredness features prominently in efforts to reform primary care. In the USA, primary care physician professional societies agreed in 2007 on an organizing concept of primary care termed the Patient-Centered Medical Home (3). Primary care

organizations in other nations have also embraced the goal of patient-centred care. Although aspiring to patient-centred care, primary care reform efforts have come under criticism for not adequately engaging patients and the public as partners in the redesign process to achieve this goal (4,5). Recognizing this shortcoming, Family Medicine For America’s Health, an initiative launched in 2015 by the major US family medicine organizations, has identified patient engagement as a strategic priority (6). In the UK, the Royal College of General Practitioners published in 2014 ‘An Inquiry into Patient Centred Care in the 21st Century’, delineating strategies to empower patients (7).

Mounting recognition that patient engagement is a fundamental strategy for achieving patient-centred care makes it important

to have a clear conceptual framework to guide inquiry and policy-making on patient engagement. One framework gaining acceptance conceptualizes patient engagement as ‘Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care’ (8). Engagement may be promoted at the individual care level, at the organizational or clinic level, and at the policy level. Most of the work to date on patient engagement in primary care has focused on the level of involving patients in their individual care. Considerable research has been conducted on individual-level engagement, such as shared decision-making and patient activation, and tools have been developed to measure and facilitate individual-level patient engagement (9,10). Much less is known about engaging patients at the organizational level, meaning at the unit of a clinic or office practice through programmes such as patient advisory councils or having patients participate in quality improvement teams. Variable nomenclature has been used for patient engagement at the practice level, such as ‘co-production’ and ‘patient and public involvement’, creating challenges for synthesizing disparate literature on the topic.

It is therefore timely to explore the role of patient engagement at the clinic or practice level. In this article, we focus on this level of patient engagement in primary care. We review the historical and policy context for the growing interest in patient engagement at the practice level, with an emphasis on the USA and UK, highlight key findings from systematic reviews of the research evidence on practice-level patient engagement and discuss practical considerations for implementing patient engagement. Our overall goal is to synthesize current understanding of practice-level patient engagement in primary care and identify gaps in knowledge that would benefit from a more well-developed research agenda on this topic.

The historical and policy context

Patient engagement at the practice level has been advocated on the basis of ethical duty (exemplified by Donald Berwick’s axiom, “Nothing about me, without me” (11)), social justice and pragmatic value for achieving better operational performance and service, that is, the triple aim of better health, better care and more affordable cost (8,12,13). The modern movement for patient engagement in organizational change in health care dates to the 1960s, when the advocacy group Mother Care for Children in Hospital successfully lobbied in the UK for unrestricted parental visiting of hospitalized children (14). Patient empowerment grew with the rise of the women’s movement, with activists demanding not just more knowledge and control over their bodies but also greater input on policies affecting women’s health (15). In recent decades, alarm about the prevalence of medical errors and patient harm has spurred greater patient and public involvement in programmes to promote patient safety, particularly in the hospital setting (16).

In the primary care setting, patient engagement at the practice level in the USA received a major impetus in the 1960s during establishment of federally funded community health centres. The Economic Opportunity Act of 1964 authorized and funded neighbourhood primary health centres to provide care for impoverished inner city and rural communities experiencing health disparities. The Act mandated that health centres have ‘maximum feasible participation of residents of the area and members of the groups served’ (17). Subsequent legislation specified that health centre patients must comprise at least 51% of a centre’s community advisory board

membership (18). Legislation charged community boards with a governing role, such as approving the centre budget and selection of a centre director, and oversight of operations, such as selecting the scope of services to be provided and operating hours. The community health centre prototypes in the USA founded by Jack Geiger embodied a progressive model of community-oriented primary care, rooted in the tradition of South Africans Sidney and Emily Kark, with deep involvement of community members in not just clinic operations but also broader social and political action to address social determinants of health (19).

With the changing political environment in the USA since the 1960s, community health centres have had to adapt to pressures from the federal government and health care marketplace emphasizing balanced clinic budgets, productivity as measured by patient visit volume and patient-centred medical home redesign. Although the social justice tradition of community-oriented primary care has not been abandoned, it is now balanced by the consumerist notion of patient centredness that favours the broader primary care reform movement. Little is known about the degree to which health centre governing boards in the contemporary era partner with clinic staff in clinic day-to-day operations, quality improvement and practice transformation initiatives. Moreover, although the 1200 community health centres in the USA play a critical role in meeting the needs of underserved populations, only about 7% of US residents receive their care from these centres. Most people in the USA receive primary care at private practices and health care organizations that have no government mandate for patient advisory boards or councils, and there has been no published systematic study of practice-level patient engagement at a representative sample of non-community health centre practices. One recent study measuring the extent of patient engagement at the practice level surveyed a select group of 112 practices that had achieved National Commission on Quality Assurance (NCQA) Patient-Centred Medical Home recognition, about half of which were small office practices rather than community health centres. Only about one-third of the practices had formal, ongoing methods of involving patients such as patient advisory councils or patient participation on quality improvement teams (20). Because these practices represent early adopters of advanced models of primary care, it is reasonable to believe that the prevalence of meaningful patient engagement at the practice level would be much lower in a more representative sample of US primary care offices. A new initiative that may facilitate greater patient engagement in practice improvement in diverse settings is the Center for Medicare and Medicaid Services (CMS) Transforming Clinical Practice Initiative. Launched in 2015, this major initiative seeks to work with more than 140 000 ambulatory care practices in the USA to improve care delivery. CMS has funded a Support and Alignment Network to facilitate greater patient engagement in practice change at the sites participating in the programme (21). In 2012, the Center for Medicare & Medicaid Innovation (CMMI) implemented the Comprehensive Primary Care (CPC) Initiative, which supported over 500 practices over 7 regions to improve primary care delivery, in which patient and family engagement in quality improvement is a core component. An expanded initiative, CPC Plus, is currently underway (22). Additionally, the most recently updated (2014) version of the NCQA Patient-Centered Medical Home requirements for the first time includes credit towards recognition for involving patients, families and caregivers in quality improvement activities or on the practice’s advisory council, which may also stimulate greater adoption of patient involvement (23). The advent of the Patient-Centered Outcomes Research Institute in the USA and its efforts

to empower patients as research partners rather than simply passive research subjects is also changing the culture for practice-level patient engagement.

In the UK, most primary care is provided by independent general practitioners and their clinic teams under contract to the National Health Service. Beginning in the 1970s, some general practitioners voluntarily established patient advisory councils, known as patient participation groups (PPGs). The Quality and Outcomes Framework for general practice payment, introduced in 2004, provided small incentives to practices to establish PPGs. By 2010, about 40% of general practices had PPGs (24). A study of PPGs concluded that the majority function 'in a subservient role to the practice', for example, by helping with fundraising or developing patient education materials and resources (25). The review highlighted a few PPGs that are deeply involved in practice management and decision-making. The new general practice contract of 2015 requires all general practices to establish PPGs. Initiatives to encourage patient engagement at the practice level also exist in Canada, Australia, New Zealand and other nations, but with little published evaluation of the extent of engagement or outcomes of these initiatives.

Evidence on patient engagement at the practice level

Ideally, the growing international interest in promoting greater patient engagement at the practice level would be matched by equally vigorous research to build an evidence base to inform initiatives and policies in this area. What methods of engaging patients succeed in achieving their aims? What approaches can be feasibly implemented and sustained in different practice settings? Unfortunately, there is a paucity of published research on patient engagement at the practice level in general and in the primary care setting in particular, with very little of the research that has been conducted consisting of rigorous, controlled studies investigating triple aim outcomes. In this section, rather than performing an original systematic review of the literature, we summarize the conclusions from systematic reviews

published since 2000 and from one additional study in primary care published after the most recent systematic review.

Most of the evidence on patient engagement at the organizational level has focused on hospitals (26). Almost all reports are case based, such as one multidisciplinary inpatient heart failure programme that had guidance from a patient advisory council and reported a 46% reduction in heart failure readmissions over 3 years relative to baseline (27). There is some evidence that patient engagement at the hospital level can improve inpatient safety in handwashing, medication error prevention and wrong-site surgery prevention (16).

In the ambulatory setting, there is limited but promising published evidence (Table 1). A systematic review from 2002 identified 42 studies, 31 of which were case studies (28). A Cochrane Review from 2009 examining the impact of consumer involvement in health care found five randomized controlled studies (29). Key conclusions from these reviews based on low- to moderate-quality evidence include that patient engagement resulted in patient educational materials that were more relevant, readable and understandable to patients, as well as changes to clinic policies and increased clinic staff receptivity to patient experience of care. A 2011 systematic review focusing on patient and public involvement in the British National Health Service found 28 studies, of which 20 were case studies; conclusions were similar to the Cochrane reviews, identifying changes in clinic policies, information dissemination and staff attitudes, but noting a lack of research evidence on clinical impact or cost (30). A cluster-randomized trial published after these systematic reviews investigating patient involvement in primary care clinic priority setting found that patients working with health professionals helped set priorities that were more aligned with patient-centred medical home principles than when health professionals set clinic-level priorities alone (31). Qualitative research based on interviews with high-functioning patient advisory councils in primary care clinics in the USA has found that staff and council members perceived that this approach contributed to improvements in clinic facilities, workflows and culture (32). Recent case studies illustrate how practice-level patient engagement in primary care has improved processes of care, such as appointment wait times, referral process to

Table 1. Evidence for patient engagement at the practice level

| Study citation | Study Design | Study Findings |
|---------------------------|---|--|
| Crawford (28) | Primarily case report-based systematic review | <ul style="list-style-type: none"> • Patients involved in health care planning experienced improved self-esteem; • Involvement led to new/improved information sources for patients, improving appointment access and improving physical access; and • For staff, working with patients improved staff attitudes towards patient perspectives. |
| Nilsen (updated 2009)(29) | Cochrane review | <ul style="list-style-type: none"> • Moderate quality evidence that patient involvement resulted in more accessible and readable patient information materials; • Low-quality evidence that consumer interviewers for patient satisfaction surveys results in less favourable reviews; and • Very low-quality evidence that telephone discussions and face-to-face group meetings for setting community health priorities result in improved patient participation and selection of different priorities. |
| Mockford (30) | Systematic review focused on UK NHS | <ul style="list-style-type: none"> • Patient and public involvement in health care impacted service planning and development, information dissemination practices and provider/staff attitudes and • Absence of evidence of clinical impact, extent of patient involvement or full implementation cost. |
| Boivin (31) | Cluster-randomized trial | <ul style="list-style-type: none"> • Patients assigned to work with staff identified clinic priorities that were statistically more concordant with PCMH principles than when staff set clinic priorities alone |

Results from a scoping literature review conducted in the Fall of 2015. Only systematic reviews and high-quality clinical trials are included within this table.

specialty care and user-friendliness of online patient portals (12,33). Preliminary findings from the 2012 CMMI Comprehensive Primary Care Initiative show that participating practices had better uptake of patient experience surveys and practices that implemented advisory councils encountered challenges finding enough time and resources to support the work. In Year two, there were increases in the number of practices reporting the use of patient advisory council feedback for practice improvement (34,35). Findings from the completed evaluation and from the 2016 CPC Plus initiative will be instructive.

Because of the paucity of research on patient engagement at the primary care practice level, a research agenda is needed to investigate what is currently being done, through what processes, and for what demonstrable impact. Cross-sectional studies describing the environmental landscape and case studies are needed to identify the extent to which primary care practices are currently engaging patients in practice transformation, looking for 'bright spots' of well-functioning models. Implementation science and robust mixed-methods study designs can elucidate how practices can successfully and efficiently establish, sustain and evaluate patient engagement strategies. Pragmatic clinical trials and patient-centred outcomes research should systematically investigate whether these strategies

achieve gains on the triple aim. Careful thought will need to be given to specifying and validating metrics appropriate for assessing processes and impact of patient engagement at the practice level, given that these are heterogeneous interventions that involve multiple stakeholders and complex systems. Methodology that borrows from industrial design and business literature, such as experience-based codesign (36) are well-suited for assessing practice improvement initiatives that involve patients. Ocloo and Matthews have pointed out that empowerment of patients and the public is itself a meaningful outcome of patient engagement, suggesting that evaluations should include measurement of patient engagement 'as something that has intrinsic value in and of itself, over and above any attempt to measure it from an instrumental perspective' (13).

Considerations for patient engagement implementation

Early evidence, although limited, is promising. Policymakers and primary care clinicians alike face a need to take concrete actions in the face of imperfect evidence. In this section, we discuss some of the pragmatic considerations in implementing strategies to engage

Table 2. Strategies for promoting patient engagement at the practice level

| Strategy (ordered from more passive to more active patient participation) | Definition | Advantages | Limitations |
|---|--|---|---|
| Patient surveys | One-time surveys given to patients to assess experience of care or components of care delivery | Quick, low cost | Unidirectional, may not capture the right data, limited responses |
| Suggestion boxes | Comment boxes in waiting rooms or exam rooms to collect ideas for practice improvement projects | Ongoing, can serve as generator for new practice improvement ideas | Typically low participation rate, needs upkeep to maintain and collect responses |
| Secret shoppers | Patients gather experiential feedback from trial phone calls to clinic or gathering step-by-step feedback on each step of clinic visit | Quick, low cost, can feed into patient experience efforts | Hard to recruit patient volunteers, data may not be representative |
| Town hall | Large-scale forum to gather community feedback on clinic initiative | Modest cost investment, if participation is high gains a large pool of feedback, patients can interact/discuss with each other at meeting | One-time feedback, may be challenging to facilitate |
| Patients as QI partners | Patients serve as members of quality improvement or practice improvement teams | Project driven, aligned with clinic QI efforts | Patient is minority among staff, may not feel supported in participating; not necessarily representative feedback |
| Patients join staff at conferences/workshops | Patients accompany staff/clinicians to academic or practice-based meetings to share experiences | Provides visibility to patient partners; patients may have unique insights to inform organizational priorities | Limited amount of patient representation, may not have clear follow-up for clinic operational improvements |
| Patient advisory councils | Representative group of 7–15 patients who meet on monthly or quarterly basis to discuss practice improvement | Bidirectional feedback, project driven, can recruit diverse/representative council, can integrate with QI efforts at the clinic | Time-intensive, higher cost, require staff time, can be hard commitment for patients |
| Patients assist in training staff | Patients participate in onboarding and training new clinical staff, particularly in patient communication | Demonstrates importance of patient perspective to new hires; builds awareness for patient experience of care | Patient partners need support and role clarity within training |
| Emerging options: virtual advisory boards/social media | Use of online message boards and social media to collect patient feedback; project-oriented patient working groups that exist for shorter term | More nimble, more action oriented, may access harder-to-reach patients such as teens or younger working families | Less tested, some concerns about online security |

Results from a cross-sectional survey of community health centres (37) as well as from experience from the field.

patients at the practice level. In addition to delineating three levels of engagement, the conceptual model of patient engagement cited earlier in this article includes an axis on the 'continuum of engagement', ranging from consultation (least engaged) to partnership and shared leadership (most engaged). In Table 2, we present an array of options that fall along this continuum, ranging from unidirectional, 'passive' forms of gaining patient feedback to more engaged, ongoing and time-intensive approaches such as patient advisory councils. A number of resources are available to help practice leaders get started (33,38,39).

Studies of the process of patient engagement have identified facilitators and barriers to successful operation. Patients selected as advisors should be representative of a clinic's patient population; successful recruitment strategies aim for inclusivity that bring in the perspectives of more vulnerable patients and patients who are willing to be constructive critics rather than just 'cheerleaders' (13,25). Staff champions need support such as protected time in order to implement patient engagement strategies. Clear workflows are necessary to review and operationalize patient feedback. Qualitative research suggests that successful programmes have communication structures in place for patient-provided data to be shared with practice leadership or quality improvement teams and provide follow-up to patients on what actions have resulted from their input (32).

Engaging patients at the practice level has its challenges. Recruiting patients requires investment of time and effort from clinic personnel, staff may be resistant to constructive criticism from patients, and there may not be clear long-term incentives for this level of participation. Recruitment can be improved by providing small honoraria demonstrating respect for patients' time. Preliminary qualitative work suggests that over time, collaboration with patient partners overcomes initial staff resistance and energizes staff to have more buy-in for patient engagement (32). However, given the many competing demands on primary care practices and the lack of clear proven benefits on outcomes from patient advisory groups, it is understandable that many practices have not prioritized patient engagement at the clinic level. Organizational-level incentives, such as NCQA Patient-Centered Medical Home recognition and UK general practice contract requirements, may provide either resources or motivation to facilitate implementation.

Conclusion

The ethical rationale for promoting patient engagement at the practice level is compelling. The social justice principle of empowering communities, particularly those subject to inequities, is a strong motivator for patient engagement among primary care clinicians caring for underserved populations, particularly among clinicians working in community health centres in the USA with a statutory mandate for patient advisory boards. Financial incentives and regulatory policies, such as NCQA recognition in the USA and general practice contract requirements for PPGs in the UK, also increase the salience to primary care clinicians of patient engagement at the practice level. Tools exist that can help clinicians to implement clinic-level patient engagement strategies. Health care funders seeking greater patient engagement in practice transformation should ensure that payment models help support the infrastructure for meaningful patient engagement.

More systematic study to better understand the process and outcomes of practice-level patient engagement and its benefits to both the practice and the patients and communities served will be important for catalysing greater diffusion of practice-level patient engagement in primary care practices across diverse settings. Although

research conducted to date in primary care provides suggestive but not yet resounding evidence in support of the triple aim benefit of practice-level patient engagement, the theoretical mechanisms are plausible and merit further investigation. As the 2011 NHS systematic review of patient engagement at the organizational level concluded, 'The lack of evidence does not indicate an absence of impact; rather it indicates inadequate reporting with a lack of valid and reliable tools to capture the impact' (30). Funding agencies should consider targeted funding in support of a comprehensive primary care research agenda on practice-level patient engagement. With well-designed implementation and outcomes research, we may be able to more rigorously measure and understand the value of patient engagement at the practice level. Whilst awaiting the results of such research, it seems only reasonable to expect that primary clinicians and organizations committed to patient-centred medical homes should meaningfully engage patients as partners in practice transformation if the goal is truly patient-centred care.

Declaration

Funding: AES is supported by a research fellowship National Research Service Award T32HP19025. KG is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through UCSF-CTSI grant number UL1 TR000004. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

Ethical approval: this study was exempted from IRB review.

Conflict of interest: KG is a member of the Engagement Tactic Team for Family Medicine for America's Health. AES has received consultant honoraria from the Western Clinician's Network for dissemination of patient engagement research. The authors have no other conflicts of interest to disclose.

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