



# Patient Engagement in Community Health Center Leadership: How Does it Happen?

Anjana E. Sharma<sup>1,3</sup> · Beatrice Huang<sup>1</sup> · Margae Knox<sup>1</sup> · Rachel Willard-Grace<sup>1</sup> · Michael B. Potter<sup>1,2</sup>

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## Abstract

Patient engagement in primary care leadership is an important means to involve community voices at community health centers. Federally qualified health centers (FQHCs) are mandated to have patient representation within their governing boards, while practices seeking patient-centered medical home certification receive credit for implementing patient advisory councils (PACs). Our objective was to compare and contrast how community health centers engage patients in clinic management, decision-making and planning within governing boards versus PACs. Qualitative study conducted from August 2016 to June 2017 at community health centers in California, Arizona and Hawaii. We interviewed practice leaders of patient engagement programs at their site. Eligible clinics had patient representatives within their governing board, PAC, or both. We assessed patient demographics, roles and responsibilities of patients participating, and extent of involvement in quality improvement among governing boards versus PACs. We interviewed 19 sites, of which 17 were FQHCs that had governing boards. Of the 17 FQHCs, 11 had also implemented PACs. Two non-FQHC safety-net sites had PACs but did not have governing boards. Governing board members had formal, structured membership responsibilities such as finances and hiring personnel. PAC roles were more flexible, focusing on day-to-day clinic operations. Clinics tended to recruit governing board patient members for their skill set and professional experience; PAC member recruitment focused more on demographic representation of the clinic's patient population. Both groups worked on quality improvement, but governing boards tended to review clinic performance metrics, while PAC members were involved in specific project planning and implementation to improve clinical outcomes and patient experience. Patient involvement in clinic improvement in CHCs includes higher-level decision-making and governance through mechanisms such as governing boards, as well as engagement in day-to-day practice improvement through PACs. These roles offer differing, but valuable insights to clinic programs and policies.

**Keywords** Patient engagement · Patient participation · Patient centered care · Medical homes

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✉ Anjana E. Sharma  
anjana.sharma@ucsf.edu

<sup>1</sup> Center for Excellence in Primary Care, Department of Family and Community Medicine, University of California, San Francisco, San Francisco, CA, USA

<sup>2</sup> San Francisco Bay Area Collaborative Research Network, University of California San Francisco Clinical and Translational Science Institute, San Francisco, CA, USA

<sup>3</sup> 995 Potrero Avenue, Ward 83, San Francisco, CA 94110, USA

## Introduction

Patient engagement within primary care clinic governance and decision-making is an important means to promote patient-centered care and incorporate the patient voice into clinic programs and policies [1]. Among primary care sites serving vulnerable populations such as low-income and publicly insured patients, patient engagement may be even more important to address health disparities, barriers in access to care, and issues related to access and health literacy [2].

Community health centers, including Federally Qualified Health Centers (FQHCs), FQHC look-alikes, and other safety net clinics, provide a substantial proportion of primary and preventive care to vulnerable and low-income populations in the United States. Community health centers serve as the primary medical home for more than 27 million

people in 10,400 rural and urban communities across America, and are based on a model of community based leadership to address local health issues with federal funding [3, 4]. Section 330 of the Public Health Service Act, which codified governmental support for FQHCs in 1944, included a mandate to prioritize patient participation within leadership of FQHCs. Specifically, FQHCs are required to have a minimum of 51% patient or consumer representation among their governing board's membership of their governing board. FQHC look-alike clinics meet similar criteria as FQHCs, but do not receive federal funding. However, they are eligible for similar Medicaid and Medicare reimbursement rates [5]. The rationale for this involvement historically included a priority to share clinic governance with the community and to allow services to be more tailored to population needs [6].

Patient advisory councils (PACs) are a newer strategy to engage patients with clinic leadership. PACs have been implemented since the late 1970s [7] but have gained more attention as a means to achieve more patient-centered care within the Patient-Centered Medical Home (PCMH) movement; PACs are listed as an optional component by which to obtain certification as a PCMH by the National Committee for Quality Assurance [8]. Medicare and Medicaid Accountable Care Organizations (ACOs), which first launched in 2011, are also required to have a PAC [9, 10]. PACs have been championed as a way to provide insight to clinic leadership on how to improve patient experience of care, as well as a means to make quality improvement initiatives more patient-centered [11]. Rigorous evaluation has not been conducted to assess the impact of PACs on clinic quality outcomes, but existing evaluations suggest that PACs improve patient educational materials and physical space, and have some impact on clinical care and priority setting for health-care leaders [12–14].

We have previously surveyed community health center leaders and found that front-line practitioners lack clarity about the differences between patient roles on governing boards and PACs [1]. The aim of this study is to define the roles of patients who participate in governing boards and PACs, comparing and contrasting them as vehicles for patients to engage in practice improvement and clinic leadership. Additional questions include understanding how patients are recruited to these activities, how demographic characteristics may differ between those who participate in governing boards versus PACs, and to what extent they participate in quality improvement.

## Methods

We used a qualitative approach to examine how safety net clinics gain input from their patients, comparing and contrasting patient roles through traditional governing boards

versus PACs. The study protocol was approved by the UCSF Institutional Review Board (16-18639).

## Study Setting

We recruited medical, administrative, and quality improvement leaders from FQHCs and safety net clinics throughout California, Arizona, and Hawaii, corresponding to Region IX designated by the Department of Health and Human Services.

## Participants

Interviewees were identified from multiple sources including: (1) The Western Clinicians Network, an association of more than 250 leaders from community health centers in Primary Care Health Services Region IX, (2) referrals from partner organizations; and (3) snowball sampling, in which we obtained referrals from early interviewees knowledgeable of other clinics with active governing boards or PAC.

Personalized recruitment e-mails asked if patient representatives at the recipient's organization are involved in a PAC, governing board, or both. We sought balanced representation from clinics with and without advisory councils and from different states in the Western United States. A phone interview lasting 30–45 min was scheduled among those who replied and met the inclusion criteria. If different individuals from the same organization had expertise in operations of a governing board versus PAC, we arranged multiple interviews. Phone interviews took place from August 2016 to June 2017. All participation was voluntary; interviewees received no reimbursement.

## Data Collection and Analysis

The study team developed a semi-structured interview guide and conducted two pilot interviews to hone the guide (see supplemental materials). Interview notes were reviewed by all members of study team. We conducted a matrix analysis [15, 16] and analyzed using a semi-inductive approach focusing on (1) patient demographics of patients recruited (2) roles and responsibilities of advisory councils versus boards of directors (3) involvement in quality improvement and/or practice improvement. Findings across these three domains were reviewed by all study team members in an iterative fashion until agreement was reached.

## Results

Leaders at a total of 19 sites were interviewed. Sites were located in California ( $n = 14$ ), Arizona ( $n = 3$ ), and Hawaii ( $n = 2$ ). Most of the sites ( $n = 17$ ) were FQHCs or FQHC

**Table 1** Site characteristics (n = 19)

Location	
California	14
Arizona	3
Hawaii	2
FQHC or FQHC lookalike	17

**Table 2** Makeup of primary care sites interviewed (n = 19)

	Governing board—yes	Governing board—no
Advisory council—yes	11	2
Advisory council—no	6	–

look-alikes; Table 1 provides an overview of clinical sites interviewed. Eleven sites had both a governing board and a PAC, six had only a governing board, and two had only a PAC (Table 2). Of the 17 sites with governing board, all except one (n = 16) had patient representatives on the board; the one site without patients on its governing board was a FQHC lookalike with a federal waiver to include stakeholder membership in place of active patients, though this site did have a PAC. Thirteen sites had implemented PACs, with 11 FQHCs having a governing as well and two non-FQHCs

having PACs only. Table 3 provides an overview of the comparisons and contrasts between governing boards and PACs at respondent sites.

## Representation and Recruitment

Of the sites with governing boards, about half (n = 9/17) reported that patient members were demographically representative of the population served. In contrast, most (n = 11/13) sites with PACs reported their members were representative of the patient population served (Table 3). The majority of sites with governing boards recruited patient members for specific skill sets or professional experience such as finance expertise, non-profit management, and business ownership. Interviewees who worked with PACs described efforts to recruit demographically representative patients that would reflect the ranges of perspectives shared by the clinic patient population served by the practice.

Of sites with governing boards, 5/17 respondents described a formalized orientation process in place for new governing board patient members, varying from individualized, clinic-based orientations to sending members to the annual National Association of Community Health Center (NACHC) board member training. NACHC was also a source of orientation documents and recruitment toolkits. In contrast, interviewees describing PACs did not typically

**Table 3** Comparison of governing board versus PAC representation and roles

	Governing boards (n = 17) <sup>a</sup>		Patient advisory councils (n = 13) <sup>a</sup>
Patient population representation (self-defined by site) <sup>b</sup>			
Representative	9		11
Not representative	8		2
Quality improvement as a responsibility of group			
Yes	15 <sup>c</sup>		9
No	1		2
Roles and responsibilities	Governing board	PAC	Examples
Community/cultural issues	5	1	Brings attention to issues in community such as gentrification, voter registration; participation in health fairs
Clinical operations and care	2	7	Provide feedback on primary and dental care; feedback on protocols and projects within clinic, e.g. review brochures, communications, patient portals, etc.
Finances (strategic fiduciary planning/resource allocation, fundraising)	10	–	Approving budgets; plan annual fundraisers; personal donations; resource allocation; capital campaigns
Higher level governance/committees/policies	7	1	Monitor and evaluate clinic performance; approving policies
Patient feedback	2	3	Discusses how to address patient complaints; patient satisfaction surveys
HR/performance reviews	4	–	Oversee hiring, firing, and monitoring of CEO

<sup>a</sup>Governing boards and PACs were not mutually exclusive

<sup>b</sup>Examples of self-defined representation included language, ethnicity, race, educational attainment, and income level

<sup>c</sup>Of these, eight specifically commented that the board focuses more on oversight

describe a formal training process for new members. Of the few that did ( $n=4$ ), this ranged from having a meeting with a staff member to having a “buddy system” where experienced PAC members would pair with newer members to orient them to the council.

Three sites with both a governing board and a PAC reported interplay between their governing board and PAC patients participants, specifically that the PAC served as a training ground and/or forum to recruit for the governing board as they gained more experience with the clinic.

### Roles and Responsibilities

Governing Board and PAC roles and responsibilities covered a broad range of topics (see Table 2). The top three roles and responsibilities mentioned for governing boards included finances (strategic fiduciary planning/resource allocation, fundraising) ( $n=10$ ), higher-level governance ( $n=7$ ), and community/cultural issues ( $n=5$ ). The top three roles and responsibilities described for PACs included clinical care ( $n=7$ ), clinic operations ( $n=7$ ) and addressing patient feedback ( $n=3$ ). Overall, the primary role of governing boards was described as higher-level oversight and strategic planning on a “big picture” level. In contrast, interviewees described the role of the PAC as being more involved in day-to-day clinic operations, such as providing feedback on educational handouts or clinic workflows.

### Involvement in Quality Improvement and Practice Improvement

Most ( $n=15/17$ ) sites with governing boards reported quality improvement as a board role. More than half of sites with governing boards ( $n=9/17$ ) described a specific quality improvement sub-committee within their governing board. For many of those sites, the board role in quality improvement focused primarily on oversight ( $n=8$ ), such as approving the annual quality improvement plan, strategic planning, or specific QI-related protocols.

For the sites with PACs, most ( $n=9/13$ ) reported quality improvement as a specific role of the group. Respondents described PAC initiatives to improve the implementation of specific QI priorities. The most common projects and tasks that fell under the purview of the PAC included patient satisfaction and patient experience surveys ( $n=5$ ); for example re-imagining an ideal clinic visit or conducting “secret shopping” to assess the customer service at their clinic. PAC members also contributed to educational materials ( $n=4$ ) related to QI, such as designing an advance directive packet or developing patient-friendly instructions for how to perform a home fecal occult blood test to screen for colon cancer.

## Discussion

To our knowledge, this is the first qualitative study to contrast different modes of clinic-level patient engagement and leadership in community health centers. The historical rationale for patient participation in community health center governing boards or PACs has been to promote the voices of traditionally underserved populations. Consumer representation within governing boards is mandatory in order to receive federal funding, so there is therefore a clear operational and financial incentive for FQHCs to involve patients in their governing boards. While PACs can provide credit on the pathway to PCMH certification, the incentive for implementing PACs may be less evident. While some leaders of FQHCs may believe that the presence of a governing board with patient representation obviates the need for a PAC, our research suggests that the demographic makeup, responsibilities and functions of governing boards and PACs are quite distinct, although complementary, with opportunities to interact.

Our findings corroborate previous research finding that governing board patient members are not demographically representative of the clinic’s patient population [17]. A lack of representativeness may have implications for service delivery; one study found that the proportion of representative patients participating in leadership positions within governing boards was predictive of scope of access-enabling services [18].

Our research suggests that the differences in the demographic makeup of governing boards and PACs are linked to their differences in role, responsibilities and function. Respondents described that governing board patient members were recruited on the basis of professional skills or experience given that governing boards have more technically complex duties such as reviewing budgets, hiring of personnel and approving protocols. PACs tend to have more intentional recruitment to ensure a demographic makeup of members that are representative of the patient population served, and community health centers with PACs have identified strategies to involve patients with a range of literacy levels and language proficiencies [19]. Future work should explore the capacity for community health center patients with limited health literacy, English proficiency or educational status to participate in the leadership roles served by governing boards; lessons learned from PACs could be applied to patient governing board member recruitment to be more inclusive.

Both governing boards and PACs address quality improvement: governing boards often have a QI committee that reviews performance metrics, while patient advisory councils tend to develop patient-centered implementation strategies for specific QI projects or activities, such as

educational materials. Both functions are important and have a distinct impact on the clinical practice. QI protocols and performance metrics reviewed by governing boards are often linked to pay-for-performance funding. In contrast, PAC insights into how to operationalize a QI project (such as how to message screening for colon cancer) may affect the success of the initiative; some research has demonstrated how community member input can dramatically change the messaging of a QI program [20, 21].

By comparing and contrasting these two modalities of patient engagement, we have identified a number of potential learning opportunities for community health center leaders. For example, training and orientation for patient members varied widely. There may be lessons and best practices in recruiting, orienting and training patients for membership across governing boards and PACs; moreover, the formalized training and orientation events and materials available at NACHC [22] may be relevant to patients who are recruited to various primary care or quality improvement advisory roles aside from governing board membership. Some sites with both a governing board and a PAC reported that the PAC served as a forum to recruit for the governing board, suggesting that at clinical sites that have both programs in place, patient members could possibly be rotated from participation in one program into another or serve in both roles simultaneously, which could foster new and useful insights for patients who participate and the clinic leaders with whom they interact.

### Limitations

This small qualitative study focused on community health centers from the Western United States that had engaged patients in clinic operations through governing boards or PACs. Further research may examine whether these findings are generalizable to other settings. Despite significant effort, we identified few safety net clinic sites without governing boards that had implemented PACs. Although this prevented us from understanding more fully how PACs operate in settings where patients do not have the opportunity for other leadership roles such as governing boards, our analyses reflect that patient representation on governing boards is a foundation at most community health centers in the United States.

There were variations in how interviewees interpreted “representativeness” of patient advisors compared to the population served. Some sites viewed representation to mean race, ethnicity, or language, whereas others considered other characteristics, such as insurance, housing status, legal status, age, or familial status. For the purposes of this study, we did not formally define “representativeness” during the interview but instead left it to interpretation by interviewees based on their own site’s priorities and populations.

### Conclusion

Our analysis suggests that community health center patients serving on governing boards have a distinct role when compared to patient participation in PACs. Governing board patient members tend to be recruited for professional skills and experience and handle higher-level operational decision-making. In contrast, PAC members tend to be more representative of the clinic’s patient population and address day-to-day clinical challenges and the implementation of specific quality improvement projects. Both are important modalities of patient engagement that are key opportunities to incorporate patient leadership within primary care among underserved populations. Community health centers working with patients in governing boards or PACs may have opportunities to share best practices and resources for orienting, training and sustaining patients in leadership roles within the primary care safety net.

### Implications for Policy and Practice

Community health centers generally include patients on their governing boards, and many are now also developing patient advisory councils. Our findings suggest that governing boards and PACs can serve important and complementary roles for engaging patients in clinic leadership. More work is needed to define these roles and develop tools for community health centers to optimize opportunities for patient engagement in clinic leadership and practice improvement.

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### Compliance with Ethical Standards

**Conflict of interest** Dr. Sharma and Ms. Willard-Grace have received honoraria for speaking engagements and providing training webinars on the topic of patient engagement in primary care. The other authors have no conflicts of interest to disclose.



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