

Bringing Patients Into the Patient-Centered Medical Home: Lessons Learned in a Large Primary Care Practice

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There is consensus that patients need to be engaged with their care, but how to do this in a primary care setting remains unclear. This case study demonstrates Patient Advisory Council engagement with the operations of a patient-centered medical home.

The passage of the Patient Protection and Affordable Care Act of 2010 (ACA) is driving dramatic change in the organization of health care. While the end state is not clear, almost all observers agree that primary care should be a foundation for the new health care system [1]. If this is the case, how do we bring a robust patient voice into the primary care setting?

What follows is a brief description of our practice's experience with developing a Patient Advisory Council (PAC) and incorporating it into the governance of our practice. Our intent is to provide a case study from the perspective of the leadership of the practice (W.P.N., D.L.P., and M.G.) and from that of our PAC (H.A.).

Setting

The UNC Family Medicine Center is a large, academic family practice providing a full scope of clinical services, including continuity and urgent care, hospital care, maternity care, nutrition, care management, and a wide variety of primary care outpatient procedures (eg, colposcopy, exercise treadmill testing, vasectomy, skin procedures, and physical therapy). The practice has about 19,000 patients accounting for 56,000 annual patient visits, and our physicians manage 2,200 medical hospitalizations, almost 400 births, and 1,000 newborns. The practice includes 36 family medicine faculty members, 26 resident physicians, 2 social work care managers, 1 clinical pharmacist, and students from all corresponding disciplines. The center's mission is to provide comprehensive care to a broad variety of patients: university and business leaders, employees of local universities and businesses, local families and their children, and a significant underserved population. Our patient population is approximately 57% white, 29% African American, 4% Hispanic, and 4% Asian. Approximately 20% of patients have Medicaid as their primary insurance, 25% have

Medicare, and 13% are uninsured.

We believe that this kind of office is a prototype for the patient-centered medical home (PCMH) of the future. Our practice was one of the first in North Carolina to achieve formal PCMH recognition from the National Committee for Quality Assurance (NCQA), in 2008, and we renewed that recognition in 2011 and 2014 [2]. The practice has been a long-standing leader both within the University of North Carolina and among other practices in its efforts related to advanced access, chronic care redesign, and other aspects of practice transformation. Finally, like many other primary care practices across the state and the country, our finances are challenging; there are no large margins to support initiatives like a PAC.

Why Start a Primary Care Patient Advisory Council?

In 2012, the UNC Family Medicine Center created one of the first ambulatory care-based PACs in a traditional practice. The foundation of this initiative was a moral conviction to share ownership of health care with patients and their families. Clinically, emphasizing patient self-management and shared decision making has been at the heart of family medicine for a generation. In addition, the first chair of our PAC (H.A.) had previously participated in a hospital patient advisory group; another of the authors (W.P.N.) had practiced for 3 years in a community health center where patients served on the practice board; and a third author (M.G.) participated on the board of a critical access hospital where the voices of patient board members were critical to operational and financial decisions. Beyond these considerations, however, we were looking for more: we wanted patients as partners.

It was clear that we needed the patient perspective to help guide the evolution of our practice. There have been

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persistent calls for dramatic changes in the model of primary care—from reports by the National Academy of Medicine [3, 4], from the Future of Family Medicine report [1], and from the Joint Statement on the Patient Centered Medical Home [5]. Following these leads, the UNC Family Medicine Center implemented advanced access [6, 7], designed new coordinated systems of care for chronic disease (including diabetes and congestive heart failure) [8, 9], and began to systematically address tobacco use in our practice [10, 11]. We obtained and renewed PCMH recognition [12], embedded social work care management [13], launched a new home-based care service, implemented interventions to reduce hospital readmissions, and built a regional system of care for uninsured patients in collaboration with partners in the UNC Health Care System [14], Piedmont Health Services, and Community Care of Central Carolina.

The outcomes of these interventions have been positive, with improvement in patient satisfaction, improvement in quality of care for chronic diseases, reduction in health care utilization (including a 37% reduction in hospitalizations for our patients with congestive heart failure), and continued rapid growth of our practice. After much review, however, we came to the conclusion that, in order to continue to progress, we needed to make further dramatic changes in our practice, including a major renovation and expansion of our clinical facility, transition to a new electronic health record system, and the implementation of a Lean approach to leading and sustaining practice improvement. Given this rapidly changing environment in which many different interventions would be implemented, we realized we had a unique opportunity to engage our patients more formally and to seek their guidance in the evolution of our practice.

The Family Medicine Center's PAC: Mission and Mechanics

After researching other models across the nation, we drafted a set of bylaws that would serve as an interim guide. We then asked our clinicians to identify patients whom we could invite to participate on the council. We conducted systematic interviews of 18 candidates and selected 10 individuals. These 10 patients organized themselves, elected a chair, framed a mission statement (see Table 1), and wrote new bylaws. The medical director of our Family Medicine Center and a key staff member were tasked with supporting the activities of the PAC. We planned meetings every 2–3 months and provided lunch; there was no additional support.

TABLE 1.
Patient Advisory Council Mission Statement

The UNC Family Medicine Center Patient Advisory Council (PAC) advises faculty and staff in their mission to develop and refine policies, practices, services, and facilities to improve the health care experience.

What is the mission of the UNC Family Medicine Center's PAC: public relations, advocacy, or advice? The only appropriate answer, according to the PAC members, was to become an advisory body. As the chair of the PAC (H.A.) emphasized, "the council's role is strictly advisory. The council has no agency or statutory authority and, as such, Family Medicine Center management may accept or reject the Council's input as it deems necessary. The Family Medicine Center is solely responsible for all Family Medicine Center policy decision whether those decisions are with or without PAC input."

From the perspective of the leadership of the Family Medicine Center, we wanted to build a partnership over time. As family physicians, we take care of patients over time, and we wanted PAC members who would partner with us to develop and improve systems designed to support these long-term relationships. Framed another way, we wanted our PAC to be more than a focus group; we wanted to systematically build the patient perspective into the governance and daily clinical operations of our practice.

After the initial organizational meetings, the PAC met bimonthly for 2 hours and reviewed critical policy topics presented by faculty members and other clinical leaders. It quickly became clear that our goal of creating a partnership with PAC members, rather than a token group of reviewers, was not being met. We then reorganized and decided to embed PAC members on core operational committees of the Family Medicine Center. Based on our needs and their interests, PAC members were assigned to key internal committees including the Family Medicine Center Steering Committee, whose duty is to oversee daily operations; the Renovation and Redesign Committee, responsible for designing the major renovation; the EPIC and Lean transformation work groups, responsible for transitioning to our new electronic medical record system and implementing Lean methodologies; and the Clinical Systems Improvement team, responsible for quality improvement. PAC members attend monthly or biweekly meetings, review data, and actively participate in events. The PAC members also review Family Medicine Center quality and patient satisfaction data, which are aggregated and without patient identifiers in accordance with HIPAA guidelines. This departmental decision to embed members in the internal operating committees was a key turning point in the development of the PAC.

Who Are the Patients on the Patient Advisory Council?

Our intent was that the PAC would be representative of our widely diverse patients and would be committed to contributing broadly regarding the care of specific diseases. Given our broad scope of practice, we wanted to include representatives of the young families in our practice, the many adults with either chronic diseases or urgent care needs, and the patients who are very sick and who use our hospital regularly. Given our racial and ethnic patient mix, it was also

important that there be racial balance as well.

In practice, we have been able to achieve our overall goals, but there have been some challenges. For example, it has been difficult to engage young families, as they have busy lives and responsibilities for managing young children. In contrast, those who are retired have more time and likely more experience in health care. We embrace prior health care experience in potential PAC members but also value members who lack this experience. Given the role we have asked of our patients and the relative youth of the council, we have found in launching the PAC that it has been important to have members with experience in developing boards and in management of health care.

What Impact Has the Patient Advisory Council Had on Our Practice?

The PAC has played a major role in helping our practice evolve. In terms of organizational impact, one of the PAC's first initiatives was to improve the signage in our 25,000 square-foot facility. They have emphasized the importance of communications, both generally—in terms of the resources available for answering phone calls and messages rapidly—and relating to specific issues, such as the phone tree for parents of young children. With respect to our renovation and redesign initiative, PAC members led a significant shift in our architectural blueprints; the patient, they insisted, should be at the center of care, with services like registration, blood draw, and referral coordination brought to the patient in the exam room, rather than the patient going to the services.

These substantive changes in the organization are only part of the impact the PAC has had on our organization. As documented in many of the articles in this issue, patients change the conversation just by being at the table. As our medical director commented, when faced with an operational or financial challenge in the practice, he finds himself asking what members of the PAC would say, and he frequently takes inquiries directly to them.

Our PAC has also had a significant impact on our academic mission. In addition to interacting with occasional students and residents, PAC members have played a direct role in providing input on clinical research. For example, one of our faculty clinician researchers was interested in addressing patients' perspectives on the value of tight control of type II diabetes, given the trade-off between possible benefits and significant side effects. PAC input, as well as their governance role in our practice, helped us win this grant, which was one of the first PCORI grants funded at the University of North Carolina at Chapel Hill. Another researcher came to the PAC for input on patient choices in screening mammography, which has become much more controversial in recent years. PAC members' input not only contributed to a research submission but also influenced a major review and adjustment in the UNC Health Care System clinical protocols.

What Is the Future Agenda of the Patient Advisory Council?

We believe that the UNC Family Medicine PAC is now well established and is ready to move into a new phase of engagement. Applications for new positions on the council have increased sharply, from 18 to over 90, and new leaders have developed a broad agenda. In addition to the ongoing and substantial work with renovation and redesign of our clinical facility, the PAC members and the leadership of the Family Medicine Center have identified significant new areas for work. As a part of Lean redesign, we have launched new approaches to hiring and developing office staff, and PAC members are interested in playing a significant role in this process, including participating in hiring of staff and orienting them to patient-centered values. Second, a year after implementing our new electronic medical record system, we now want to take better advantage of its patient portal. This is a potentially powerful tool to enhance communication and coordination of care; our hope is to use it to close gaps in preventive and chronic disease care. We will need ongoing input from patients to do this effectively. Finally, as insurers begin to pay for value rather than for volume of services provided, we need patients to help us develop programs that feel right to them. We want patients to help drive our assessment of what constitutes value and to engage them in the organization of their own care.

What Challenges Have We Faced Along the Way?

We know from our colleagues in other primary care practices that developing a PAC is challenging. Getting the right people on the PAC has proved critical, as has engaging providers. Providers spend considerable one-on-one time with patients; they see patients when things are going well and when things are not going well. Getting providers' recommendations as to who would be a good PAC member was very helpful.

A second challenge has been keeping members engaged. Patients may come with hidden agendas or misconceptions about the true nature and purpose of the council. It was therefore paramount to develop an effective intake program to provide new PAC members with a definitive view of what they can expect to do while serving on the council. Members need to be very clear on the purpose, scope, and parameters of the council. This is critically important to ensure that everyone is adhering to legal and policy constraints.

Another challenge is finding meaningful roles for council members with specific interests and strengths. We seek to balance the needs of the Family Medicine Center with the interests of individual members; while largely successful in this goal, we have lost PAC members for whom that balance was missing. In addition, deciding how and when to meet can be difficult; parking, food, and time of day can all be challenges.

The most important asset we had was commitment from all levels of departmental leadership. PAC members have had direct access to staff, clinicians, and department leaders, and they value this connection and support. We seek to have PAC members understand that we truly value their opinion.

Conclusions

We have demonstrated that, in the right setting, robust patient leadership and a clear mission can empower a PAC to have a dramatic impact on a complex primary care practice. We believe that a primary care PAC is quite different in culture and outlook from a hospital-based PAC. We are also keenly aware that there are likely many different ways of having successful PACs and that what has been possible in our large practice and community may be difficult in other settings. In talking with other primary care practices that are trying to establish PACs, it is clear that the micro-environments of each practice—the practice's history and culture, the management style of practice leaders, and the personalities of the clinical and patient leadership—are all crucial for developing a robust and sustainable PAC. Moreover, as with other aspects of practice transformation [15], early success is important; the initial projects that are undertaken must make a meaningful difference. In the end, as our practice is forced to evolve rapidly, we are delighted to have our patients as partners. Our lens is much more patient-centered, and we are better for it.

More broadly, as health care moves out of hospitals, we believe that embedding patients into the operational structure of primary care practices will become increasingly important. As health systems consolidate, the right relationship between hospital-based PACs and primary care PACs will need to be worked out. We will also need to experiment with models of PACs that are feasible within the small primary care practices that play such an important role in health care. Finally, we recommend building functional PACs into medical home recognition programs from the NCQA and other organizations. As with other aspects of primary care, our goal is to do more than to just check off a box on a list. We want patients to have a real role in transforming primary care practices. **NCMJ**

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