Journal of Patient Experience
Volume 10: 1-4

DOI: 10.1177/23743735231184692
journals.sagepub.com/home/jpx

Implementation of a Novel Telehealth Patient Advisory Council

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Abstract

Patient engagement in healthcare delivery processes has been increasingly emphasized in recent years, which can be accomplished in part by Patient Advisory Councils (PACs). Although well-established in brick-and-mortar facilities, the use of PACs in pure telehealth settings is limited. Bicycle Health, a digital health organization that provides biopsychosocial treatment of opioid use disorder (OUD) via telehealth, sought to increase patient engagement regarding care delivery and innovation, ultimately launching a telehealth Patient Advisory Council. Herein we discuss implementation challenges and iterative changes to address each challenge. Key learnings include the following:

1. Patients with OUD are often subject to significant stigma, including by healthcare professionals. This is a key factor to consider when recruiting and engaging patients; trust building is key and can help to overcome both perceived and actual stigma.
2. Inclusion of core staff persons who have lived experience with the respective health condition—in this case, OUD—is beneficial.
3. Utilizing a formal framework, such as the Model for Improvement (utilized widely by the Institute for Healthcare Improvement), to guide improvement work is helpful for providing structure to feedback conversations, though this framework should be presented to patients in accessible language.

Keywords

patient advisory councils, telehealth, telemedicine, quality improvement, innovation, opioid use disorder

Introduction to the Issue

Patient engagement in healthcare delivery processes has been increasingly emphasized in recent years. Rather than patients participating only in their individual care, patients are also contributing to organizational delivery, quality improvement, and innovation. Patient engagement can be accomplished in various healthcare systems via Patient Advisory Councils (PACs) or Patient and Family Advisory Councils (PFACs). These councils are defined as "groups of patients, family members, and caregivers who meet on a regular basis to help identify practice improvement priorities and support practice improvement projects in collaboration with clinic staff members and leaders."[1]

PACs are well-established in brick-and-mortar facilities, though their use in pure telehealth care delivery settings is limited. The literature that does exist describes PACs that began as in-person PACs and transitioned to remote meetings amidst the COVID-19 pandemic.[2]

Bicycle Health, a digital health organization that provides biopsychosocial treatment of opioid use disorder (OUD) via telehealth, sought to increase patient engagement regarding care delivery and innovation.[3] Thus, a purely telehealth Patient Advisory Council (tele-PAC) was assembled to better identify opportunities for care delivery improvement.

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The core tele-PAC staff were assembled by organizational leadership and tasked with development and implementation. Core staff included medical providers, clinical support staff, and members of the leadership team. Prior to patient recruitment, tele-PAC staff developed criteria for patient inclusion. These criteria were based on the Agency for Healthcare Research and Quality (AHRQ) implementation handbook, "Working With Patients and Families as Advisors,"[4] as well as the Bicycle Health mission and vision for treating patients with OUD. Criteria include the following:

- capacity to represent the patient care experience;
- willingness to work respectfully and collaboratively;
- demonstrated concern for more than a single issue;
- good listening skills;
- positive, constructive attitude;
- ability to maintain confidentiality;
- commitment to support the organization's recovery community; and
- investment in personal recovery and growth.

Patient recruitment for the novel tele-PAC was initially accomplished by asking all medical providers to recommend at least 2 patients for participation. Core tele-PAC staff then screened the recommended patients for eligibility and invited select patients to participate in the tele-PAC via the organization's telehealth platform. This recruitment approach broadened over time, ultimately permitting all organizational employees to refer patients to the tele-PAC.

With this broadened recruitment approach, 34 patients expressed interest in joining the tele-PAC, 8 signed the Acknowledgement, 7 attended at least one meeting, and 4 patients were ultimately retained in the initial Patient Advisory Council. The attrition from the initial group that expressed interest was largely due to scheduling conflicts and misunderstanding of the purposes of the tele-PAC.

Before patients attended their first tele-PAC meeting, they were required to sign the Patient Advisory Council Acknowledgement, which states that by participating in the tele-PAC, they will be making their status as a Bicycle Health patient known to other patients also participating in the tele-PAC. This signed Acknowledgement is permanently stored within each patient's respective electronic medical record. This step is required by 42 CFR Part 2 regulations, which Bicycle Health adheres to given its patient population and treatment services.[5]

The tele-PAC meets monthly and continues to develop in its maturity. Initial meetings focused on trust building, information sharing, and informal feedback regarding Bicycle Health services. After listening to the lived experiences and challenges faced by patient advisors, the core tele-PAC staff discussed process implementation for turning feedback into actionable improvement projects. More recent meetings have applied the Model for Improvement (utilized widely by the Institute for Healthcare Improvement), which poses the following 3 questions[6]:

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What change can we make that will result in an improvement?

Through the use of this framework, core tele-PAC staff help patients to "identify advisor activities, match advisors with activities, provide coaching and mentoring, and track and communicate advisor accomplishment," as outlined in the AHRQ implementation handbook, "Working With Patients and Families as Advisors."[4] Quality improvement topics addressed by the tele-PAC thus far include the development of community-facing educational materials with evidence-based information about OUD and its treatment, financial support options for patients in need, and initiatives to increase support group involvement. Specifically, the Information Handbook developed by tele-PAC members will allow newly onboarded patients to establish a sense of trust within the recovery community, including among their respective Bicycle Health providers and staff persons. This handbook will also provide patients with additional tools to discuss their diagnosis with family members and other health professionals.

The tele-PAC was originally conceived to include family members. However, during initial council meetings, it was agreed upon that Bicycle Health's inaugural tele-PAC would benefit from the participation of only patients and staff. This decision was made in order to promote trust building, establish mission and vision for the council, and overcome any perceived stigma that prospective patients may encounter in consideration of joining the tele-PAC. The decision of whether to include family members will be reevaluated annually.

Key Factors for Consideration

Engaging patients in this type of patient-centered care initiative has presented novel challenges. The primary barrier to successfully launching the tele-PAC was patient recruitment in a remote environment. The multistep recruitment process initially resulted in a small number of invited patients, which differed from the "broad net" recruitment approach recommended by the Institute for Patient- and Family-Centered Care.[7,8] Specifically, limiting the pool of individuals (to medical providers only) that were asked to identify suitable patients resulted in lower-than-expected recruitment numbers. After successfully recruiting 3 patients over a 3-month period with this approach, it was determined that eligible patients could be recommended for the tele-PAC by any staff member.

A secondary challenge faced in developing the tele-PAC was utilizing language at an appropriate comprehension level in our recruitment materials. Initially, the language used was too formal, which created another barrier to a successful tele-PAC launch. During the inaugural meeting, a patient advisor recommended new recruitment messaging that was more casual and personable to patients—an exemplar of the benefits of increasing patient involvement in care delivery.

As a result of these early challenges encountered in the recruitment process, initial tele-PAC meetings were disproportionately attended by core staff members. To address the imbalance of attendees, the monthly meeting date and time were adjusted to accommodate the schedules of 2 additional patients. Core tele-PAC staff also adjusted the recruitment strategy as previously discussed and initiated additional outreach. The tele-PAC is now comprised of 8 patients (with a total of 12 ever-involved tele-PAC patients).

Another challenge included focusing tele-PAC attention on its mission to address quality improvement work. Because a key component of the initial tele-PAC meetings included trust building, which resulted in meetings that were largely governed by icebreakers, information sharing, and informal feedback, it became challenging to shift the tele-PAC focus towards a quality improvement framework. The Model for Improvement was introduced during the sixth council meeting and has been applied during most subsequent meetings.[6] With this framework, tele-PAC members generate improvement questions and evaluate the role of the tele-PAC in addressing that improvement work.

Recommendations

Our experience developing this tele-PAC leads us to the following recommendations (while this tele-PAC is focused on OUD, we expect that these lessons can be generalized to other conditions as well):

- Patients are more receptive to joining the tele-PAC after discussing the opportunity with their medical provider or therapist.
- A balanced patient-to-staff ratio is of critical importance for patient comfort and trust building.
- Patients with OUD are often subject to significant stigma, including by healthcare professionals.[9] This is a key factor to consider when recruiting and engaging patients; trust building is key and can help to overcome both perceived and actual stigma.
- Inclusion of core staff persons who have lived experience with the respective health condition—in this case, OUD—is beneficial.
- PACs published in the literature have traditionally started their work by collectively writing bylaws and mission statements, which can be useful for defining mission, vision, values, and scope of work.[7] Our experience is that the formality of this specific type of work was intimidating to the initial patient members. It may be beneficial to delay this work, especially writing bylaws, until recruitment and trust building is complete. Placeholder bylaws can be developed by core staff prior to the first meeting, then replaced by new bylaws developed by the complete tele-PAC membership after recruitment and trust building have been completed.
- Utilizing a formal framework, such as the Model for Improvement (utilized widely by the Institute for Healthcare Improvement), to guide improvement work is helpful for providing structure to feedback conversations, though this framework should be presented to patients in accessible language.

There remains a dearth of quantitative evaluation of PACs in the published literature.[10] As our tele-PAC furthers its structured quality improvement work, we plan to develop quantitative and/or qualitative evaluation plans for each project. This will enable patients and leadership to understand the value of this investment more fully, as well as contribute to the literature regarding the utility of PACs in improving the quality of healthcare delivery.[11]

Conclusion

A purely telehealth PAC is a forum for patients and staff to work together to improve healthcare service delivery, as well as direct community engagement and advocacy. We hope that the challenges, lessons, and recommendations presented will help inform other purely telehealth organizations of the benefits of establishing their own tele-PACs, as well as inform their implementation strategies.

Acknowledgments

The authors would like to thank Rafael Caycho, PhD, MHA, and Jennifer Harris, MSN, for their roles in the Bicycle Health Patient Advisory Council.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Authors Rebekah Rollston, Winifred Gallogly, Alex Lynch-Coffey, and Liza Hoffman are employed by Bicycle Health, Inc. and receive income from Bicycle Health, Inc. Author Brian Clear is employed by Bicycle Health Medical Group and receives income from Bicycle Health Medical Group. Winifred Gallogly, Alex Lynch-Coffey, Liza Hoffman, and Brian Clear have been granted equity in Bicycle Health, Inc.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Ethics Approval

Ethics approval is not applicable to this article.

Statement of Human and Animal Rights

This article does not contain any studies with human or animal subjects.

Statement of Informed Consent

There are no human subjects in this article, and informed consent is not applicable.

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