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Emmanuelle Trépanier  
*Université de Montréal*

Marie-Pascale Pomey  
*Université de Montréal*

Paule Lebel  
*Université de Montréal*

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The authors wish to thank the patient advisors and all the participants from the Verdun GMF-U and the CIUSSS du Centre-Sud-de-l'Île-de-Montréal who participated in the study. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (https://www.theberylinstitute.org/ExperienceFramework). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

This case study is available in Patient Experience Journal: https://pxjournal.org/journal/vol8/iss3/17
Patient engagement in an academic community-based primary care practice’s management committee: A case study
Emmanuelle Trépanier, Université de Montréal, emmanuelle.trepanier@umontreal.ca
Marie-Pascale Pomey, Université de Montréal, marie-pascale.pomey@umontreal.ca
Paule Lebel, Université de Montréal, paule.lebel@umontreal.ca

Abstract
Patient engagement in primary care has been the focus of many studies; however, little research has evaluated its added value to organisational management in an academic community-based primary care practice (ACBPCP). In 2017, managers of an ACBPCP in Montreal, Canada, decided to integrate patients into the organization's management committee to enhance the quality and relevance of decision-making for clinical services, education and research. Objectives were to 1) assess patients' role and influence on an ACBPCP management committee’s decision-making process; 2) identify the facilitators of and obstacles to patient involvement in this context; and 3) evaluate the impact of this innovative approach in promoting a patient partnership culture throughout the organization. Using a single case study, qualitative and quantitative data was collected between June 2017 and May 2019 from three levels: 1) professionals in charge of patient partnership working within the territorial health care organization’s quality division; 2) management committee; and 3) ACBPCP’s staff outside the committee. Successful patient governance relies on a structured engagement approach, including a rigorous recruitment process, joined training and coaching of all committee members and the development of work modalities that facilitate co-construction. Multilevel leadership is also fundamental to support a partnership culture throughout the organisation. The results of this study illustrate opportunities and challenges related to patient involvement at an ACBPCP’s organizational level. They can guide other community-based primary care practices interested in involving patients in their management activities.

Keywords
Patient engagement, patient partnership, governance, primary care, academic community-based primary care practice, organizational management, co-construction, patient experience, Canada

Background
Over the past decades, health care systems worldwide have adapted to the increasing prevalence of chronic diseases and the complex and long-term care they require. This transition toward chronic care at a clinical level was accompanied by systemic awareness about the importance of patients’ engagement at all levels of the health care system as a strategy to improve and sustain health care delivery. In Canada, 65% of individuals aged 12 and older and 90% of individuals over 65 years old have declared being affected by at least one chronic condition. Analysis of the health care system stressed the importance of patient and public participation in health care governance and of strategies fostering their engagement. Demonstrated benefits of patient engagement include “reduced hospital admissions, improved effectiveness, efficiency and quality of health services, improved quality of life, and enhanced quality and accountability of health services.” It was also demonstrated that, by involving patients in strategic planning, health care priorities became more aligned with components of the Patient-Centered Medical Home and the Chronic Care Model.

Patient engagement in a health care organization’s governance can take place at the operational, tactical or strategic level. In academic institutions, patients also take part in research and teaching activities related to health care professions.

In 2017, managers of an academic community-based primary care practice (ACBPCP) in Montréal, Québec, Canada, decided to include patients on their management committee. The selected patient advisors were expected to take part in the strategic planning by sharing a patient’s point of view on the services encountered and the ACBPCP’s academic priority. Patient participation at the clinical level, in quality improvement initiatives and in health organizations’ governance activities, has been the focus of several studies. However, to our knowledge, no research has evaluated patient engagement at the strategic level of an academic primary care setting. The current study aims to look at this dimension. The
objectives of this study are to: 1) assess patients’ role in and influence on an ACBPCP management committee’s decision-making process; 2) identify facilitators of and obstacles to patient engagement in this context; and 3) evaluate the impact of this innovative approach on the promotion of a patient partnership culture throughout the organization.

Study Setting

Presentation of the ACBPCP

This study takes place at an ACBPCP called Verdun GMF-U (also referred to as a Groupe de médecine de famille universitaire), which brings together over 60 family physicians and residents in training. Family physicians are remunerated on a fee-for-services basis.\textsuperscript{16,17} This GMF-U is one of the largest ACBPCPs in the Department of family medicine at the University of Montreal. GMF-Us are frontline flagship settings that abide to the family medicine principles of accessibility, coordination of care, prevention and health promotion and that aim to provide high-quality care and services.\textsuperscript{16,18,19} At the regional level, the Integrated university health and social services center (called Centre intégré universitaire de santé et de services sociaux (CIUSSS)) is in charge of the population health of its territories. It provides financial and human resources (nurses, pharmacists, social workers, etc.) based on the number of patients registered and the services provided by the clinic. The CIUSSS also provides resources to implement patient partnership at all organizational levels, to improve the quality and security of health care.\textsuperscript{16,20} Furthermore, GMF-U’s management framework developed by the Quebec Ministry of Health and Social Services supports the integration of patient advisors or representatives in this kind of institutions.\textsuperscript{18}

The ACBPCP committee’s mandate is to ensure the organization’s response to the three aspects of its academic mission, namely clinical services, teaching and research, and to evaluate the organization’s service offering and performance based on key quality indicators. The committee members, which include patient advisors since 2017, meet six times per year.

The patient integration process

The Centre of Excellence on Partnership with Patients and the Public (CEPPP), which works in partnership with the University of Montreal’s Faculty of medicine, has developed an expertise on engaging patients at the different levels of governance of the healthcare system.\textsuperscript{9} At the ACBPCP, a structured selection process was carried out by a patient recruiter and an expert on partnership from the CEPPP duo, according to pre-established criteria based on the work of the CEPPP: a) experiences with illness and the health care system, b) personal abilities and attitudes, and c) availability.\textsuperscript{21} Thirteen patients recognized as partners in their own care plan or that of a family member were identified by their physician as potential patient advisors. Telephone and in-person follow-up interviews were carried out with five of them. The patient recruiter had already been involved in management and quality improvement activities at the ACBPCP and was to be included on the management committee. Two other patient advisors were recruited; one was a caregiver, and the second was a patient with a common medical condition among the ACBPCP’s patient population.

Once recruited, the patients received two two-hour training sessions to provide them with the basic knowledge of the healthcare system and the management framework of the ACBPCP. It also aimed to teach them about co-construction and how to put forward their experiential knowledge. Furthermore, two professionals from the CEPPP, one patient expert and one senior advisor, were mandated to coach the committee members in the implementation of the co-construction process with the patients. From June 2017 to September 2018, they attended the committee’s meetings as observers and provided the co-facilitators and patient advisors with individual coaching.

Conceptual Model

In the past decade, the Direction of Collaboration and Patient Partnership (DCPP), the educational entity of the CEPPP, was implemented within the University of Montreal’s Faculty of medicine to improve its capacity for patient partnership by fostering research in that area and providing guidance for curriculum revision.\textsuperscript{22} Based on the DCPP’s “Montreal Model” framework,\textsuperscript{9,10,23} the current innovation takes place at the “meso” level of the health care system (Table 1).

The patients were recruited to join the ACBPCP’s management committee and collaborate in a “co-construction” process with the other members, defined as: “a way for patients and professionals to collaborate, based on their complementary individual expertise and experiential knowledge and on shared leadership, in order to accomplish a joint activity stemming from a shared understanding of an objective and the process needed to achieve it [free translation].”\textsuperscript{24}(p.8)

Experience sharing is key to the co-construction process.\textsuperscript{25} Once reflected upon, the experience is translated into cognitive but also emotional and sensory learning — a key element to designing a positive health care experience that goes beyond purely technical services and process goals.\textsuperscript{26}

The study is also based on the Quebec Ministry of Health and Social Services’ framework\textsuperscript{27} for the partnership approach between users, their families and health and social services stakeholders, as well as Pomey’s article,\textsuperscript{22} which explicitly exposes fundamental partnership issues.
and success conditions, including a continuous improvement process, dedicated resources, management leadership and an implementation, sustainability and follow-up structure.

Methods

Design
The proposed research strategy involves a single case study with three embedded levels of analysis. This design was chosen as it allows for an in-depth and longitudinal analysis of the processes at work within their specific context, which influences the phenomenon under study, namely the ACBPCP integrating patients into its management committee.

The three levels of analysis are: 1) the professionals in charge of patient partnership working within the CIUSS's quality division; 2) the ACBPCP management committee members; and 3) the ACBPCP's medical and non-medical staff.

Participants and data collection
Study participants were recruited from the three levels of the case study (Table 2). Qualitative and quantitative data was collected between June 2017 and May 2019.

For the CIUSS's professionals in charge of patient partnership working within the quality division, one semi-structured interview was carried out. Their contribution was essential to better understand patients' contribution to health management and associated challenges.

At the ACBPCP management committee level, all committee members were recruited to take part in the study, as well as the two coaches from the CEPPP. The sample is non-probabilistic, made by deliberate choice based on the aim of the case study. This level’s body of data first came from a group discussion with all the committee members as part of a meeting. Notes taken during the discussion were included in the corpus. A second group discussion was organized with the two co-facilitators of the management committee and the two coaches from the CEPPP. It aimed to understand the patient advisors’ selection process in greater detail, as well as the expected and actual role they played. Individual semi-structured interviews were also carried out with each of the patient advisors, in order to understand their experience and identify facilitators and obstacles to patient engagement in this context. Conducted by the PI (ET), the interviews lasted between sixty and seventy-five minutes, were audio-recorded, transcribed and anonymized.

Documents used by the management committee were also analyzed with the intention to find out at which level of engagement the patient advisors were invited. These documents included agendas, meeting minutes, the committee’s mandate, as well as any communication considered relevant to the analysis of the case study.

For the ACBPCP's medical and non-medical staff, data came from an online modified version of the Readiness to Partner With Patient and Family Advisors questionnaire. All health and non-health professionals from the ACBPCP were solicited by email and in person, during an academic meeting. Thirty-one among one hundred and two (30%) agreed to participate in the study. Statement questions in the form of Likert scales were created in order to grasp the state of play of the organization in terms of openness to patient partnership.

Finally, the PI (ET), who is also a member of the management committee as a clinician with research responsibilities, used a study logbook as a reflective tool to ensure the transparency and integrity of the study’s process.
Analysis
An inductive approach guided the analysis of the data. In an iterative process, the analysis of the qualitative data was first performed at each level of the case study, and subsequently cross-functionally through each level. A theme-based codification technique guided the analysis. The PI (ET) was responsible for compiling and coding the entire data set, and a quarter of the data was analyzed by two authors (ET and MPP) to validate the coding and increase objectivity. The documents were analyzed using a structured grid focused on their accessibility in terms of health literacy and their ability to promote shared decision-making. Finally, answers to the questionnaires were analyzed using proportions of agreement to the statements.

The collection of data from various sources allowed for increased credibility of the analysis and transferability of the results through triangulation.

Ethics
The study was approved by the CIUSSS du Centre-Sud-de-l’Île-de-Montréal’s ethics committee (DIS-181) and the University of Montreal’s health care research ethics committee (18-072-CERES-D).

Results
Based on the various data sources, the following section presents the findings related to the role and influence of patient advisors, facilitators and obstacles to their engagement, as well as the factors that contributed to the patient partnership culture within the ACBPCP.

Patient advisors’ role and influence
The reason patient advisors were initially recruited for is to share their perspective based on experiential knowledge from the disease and the use of health care services. Cumulative data highlights specific roles that patient advisors played during their tenure, such as advocating for patients, challenging established processes and bringing up current population health issues for the committee to address. However, in general, the patient advisors’ interventions consisted in getting information by asking questions of clarification, as mentioned here:

“You know, sometimes… I feel as though what a patient partner really brings to the table is questions.” (Patient)

In fact, patient advisors’ spontaneous interventions were sparse. They mostly took place when solicited, with the concern not to contradict. Indeed, they still considered themselves more as patients and less as members of the committee, as suggested by this quote:

“As a patient, you’re so used to not being on equal footing with any of the staff sitting at the table, and your experience so far is ‘daddy’s right,’ daddy being the doctor.” (Patient)
In terms of influence on the decision-making process, the patients’ contribution took place through its impact on interpersonal dynamics. For professionals, this new collaboration structure means they become co-workers with patients. In addition, they might feel exposed and more vulnerable in some way, as professionals, but also as potential patients. The following quotes reflect this information:

“… I think it’s human too, we want to keep our problems to us, you know. […] I think it is a question over time also of being confident, that the patients are not there to judge, but they are there […] in co-construction mode, if you will.” (Patient)

“It’s kind of special, but it reminds us all that in the end, we’re all potential users if we aren’t users already, so we have to be more human, to treat them more like equals.” (Professional)

One memorable example of patient advisors’ influence took place when the management committee discussed a regulation concerning appointment delays. Patient advisors, who disagreed with the preliminary decision, objected, and based on their intervention, the final decision was significantly altered and “humanized” to better accommodate the clinic’s clientele, as mentioned in the following statement:

“… when you brought up the issue of patients […] being late to appointments, you changed your policy on that thanks to patients’ feedback. And that’s a big deal.” (Professional)

Regarding the management committee minutes and agendas, they included discussion and decision items, but mostly information ones, therefore limiting the opportunity for patient to bring forward their experiential knowledge.

**Facilitators and obstacles to patient engagement**

First, for patient engagement to take place in an optimal way, a rigorous engagement process was put in place. The patient advisors recruited had variable professional backgrounds, levels of education, experiences with managerial activities and personal experiences with illness, but they all regularly attended the ACBPCP services. Integration was easier for patients who had basic managerial skills, as it gave them more self-confidence and facilitated intellectual effort:

“Now, the flipside of having someone who doesn’t have that [management] background is that you’ll have to bring them up to speed not only on the health care system, but also on basic management or administrative concepts […] in that case, you have to account for more time.” (Patient)

In terms of training, data highlighted the importance of making expectations clear from the start. It is essential that patients be informed of the potential challenges of governance and get prepared for it during recruitment and training, which could be improved, based on the results. Motivation and the tedious and slow decision-making process are examples of the challenges encountered, as recalled by theses interventions:

“… the patients are impatient to see things happen […] so if you want a participation, the counterpart to it is to deliver. It’s a give and take this thing.” (Professional)

“… this is an important element […] to always have small achievable goals in the very short term, a little modest just to keep people motivated, involved, engaged…” (Professional)

“… I also understood that it’s like really, really hard to move a comma, even (laughs).” (Patient)

With regard to coaching, the main source of guidance came from the other patient advisors, as mutual support has developed between them. This was particularly the case for the patient who was already engaged in the ACBPCP’s activities and played a mentorship role for the others:

“Look, most of the suggestions, plus the conversations I’ve had, are with [patient partner] […] After a meeting, sometimes we would talk on the phone…” (Patient)

Furthermore, facilitation was identified as an important element of the engagement process. Facilitation must promote the participation of all members by ensuring everyone’s understanding and the avoidance of jargon, designating the speaking turns and playing a timekeeper role. In this case, facilitation was assumed by two people, the ACBPCP’s clinical chief and its manager, both co-chair of the committee. Facilitating the committee is a demanding task. Indeed, there is a delicate balance between inquiring the point of view of those who would not dare to express themselves spontaneously and unwanted solicitation, as this quote suggests:

“… they would use their jargon and be like ‘alright, let’s debate this’ and stuff. And oops, at one point, well, they would ask me a question and I’d always have to stay on my toes a bit to answer it, you know, like ‘what do you think of this as a patient?’” (Patient)

Finally, in terms of obstacles, the current political and organizational enthusiasm around the “patient engagement” approach in health, as well as the criteria for selection or funding of projects, induce pressure on organizations, which creates the risk of a certain instrumentalization of patients. Some participants fear
that, in order to meet the standards, teams will engage in a partnership approach, but with no real aspiration to work in co-construction, a concern raised by more than one participant. Therefore, recognizing and promoting the impact of their individual contribution can not only be motivating, but also a guarantee that their contribution is not merely tokenistic. The following quotes reflect these concerns:

“… at one point I said, ‘Is that just a fashion?’” (Patient)

“… it’s a little bit fashionable, if you want, to have patient partners: everyone wants patient partners. […] So, you’re asking yourself as a patient, ‘What am I doing in there? Am I useful?’ and all.” (Patient)

“… the credit for the idea is not attached there, throughout the process. For the patient advisors I think [it would be good] because suddenly there you really feel like you have actually been useful… it’s the only pay we have.” (Patient)

“What’s difficult for the future is for us to always feel that we’re useful and helping to advance things, that we’re part of the solution, we’re part of the committee and not just there out of a moral obligation of sorts, you know.” (Patient)

**The ACBPCP’s partnership culture**

In an avant-garde way as an academic primary care environment, the ACBPCP under study included patient advisors on its management committee, while the managers presented themselves as leaders, as reported below:

“…leading by example is also extremely important symbolically. A director who doesn’t associate with patients or who isn’t capable of reaching them or of being on their level, equal with a patient, can’t ask his employees or the professionals around him to do so. […] I think that it’s a super important part of bringing about a shift in culture.” (Professional)

In terms of a partnership culture on the committee, certain characteristics are favorable not only to a trustful relationship but to a co-construction approach more broadly, such as openness, humility and maturity.

“People have to be open-minded; they have to be humble.” (Professional)

“But it really takes work on oneself, maturity to be able to say: ‘Ok, I must be able to accept that the other […] will bring something complementary to me and that he can bring myself to review my way of seeing things, to review my ways of working and to take decisions that would have been made otherwise if I had not considered, ultimately, the words that this person shares with me.’” (Professional)

In addition, most of the professionals outside the committee demonstrated openness to a patient-partnership approach in governance, as the answers to the Readiness to Partner with Patient and Family Advisors questionnaire indicate. Of the thirty-one respondents to the questionnaire, 83.9% agreed or strongly agreed to the statement “I believe in the importance of the participation of patients and relatives in the governance of the ACBPCP”, 87.1% agreed or strongly agreed to “I believe that the views and opinions of patient advisors, staff and clinicians are equally valuable for planning and taking organizational decisions” and 67.7% agreed or strongly agreed to “I am or would be interested in collaborating on activities in collaboration with patient advisors within the ACBPCP.”

However, 69% disagreed or strongly disagreed to the statement “I noticed changes within the GMF-U since patient partners have been involved in the executive committee”, suggesting a hermetic aspect to the change taking place on the management committee.

**Discussion**

This study allowed us to highlight the rigorous process put in place to facilitate patient engagement at the governance level of an ACBPCP. The approach aimed to create the conditions necessary for patient advisors to play their role in an optimal way. However, the results show a limited influence on decision making and a limited impact on the promotion of a patient partnership culture outside the management committee. The following section will discuss the results and several reflections raised during the study.

**The engagement of patient advisors: a collective process**

The factors facilitating the engagement of patient advisors on an ACBPCP’s management committee can be summed up in a structured engagement process which includes identification and selection based on pre-established criteria, training and coaching, as well as co-facilitation. The results are consistent with strategies identified in the literature to enhance patient engagement and which include careful selection of patients, clear expectations towards them, as well as prior training and continuous coaching.°

The study results show that these conditions are essential, but not sufficient. Engagement of patient advisors at the governance level of the ACBPCP is based on a co-construction approach between professionals and patient advisors and a paradigm shift in terms of occupational identity is required in order for all members to truly engage in a co-construction process.

On one hand, patients must be able to “harness their experiential knowledge to represent a ‘patient’s perspective’ in interactions and the decision-making
process [free translation].”\(^{21(9)}\) Their contribution relies on the right balance between experiential knowledge and their ability to put it to use; it is fundamental to the role and influence they play. However, based on the study results, explicit and spontaneous sharing of experiential knowledge remained sparse, limited by a feeling of inequality between members. For patient advisors, speaking out meant challenging the power asymmetry that comes with the classic doctor-patient relationship.

Therefore, on the other hand, the recruitment of the committee’s non-patient members should also be sensitive to fundamental skills and characteristics, like openness. Also, professionals must agree to reveal a certain vulnerability, while patients take cognizance of the organization’s strengths and weaknesses.

Moreover, literature reminds us that factors of resistance to change include a lack of information.\(^{39}\) Therefore, prior training of committee members and patient advisors together might be an opportunity for all members to learn about co-construction, in an equal learner position, which might enhance the partnership culture on the committee.\(^{22}\)

In terms of coaching, the ACBPCP’s management committee did have initial coaching. One patient advisor with more experience also positioned himself as an informal coach and provided moral support for the other advisors. Based on the literature however, it could be beneficial to maintain a certain level of coaching through regular debriefing with all the committee members, combined with a revision of group objectives, as a continuous improvement opportunity to enhance the engagement capacity of the committee.\(^{40}\)

Finally, in order to establish a true co-construction approach, work modalities must allow for the focus of the discussion to shift towards experiential knowledge sharing, which relies in part on meeting planification, but mostly on strong mediation. Part of the facilitator’s role is to engage with members equally, to ensure the agenda and pace are respected and to create and maintain a respectful atmosphere. Expectations are high, as facilitators play a significant yet sensitive leadership role in the proper functioning of the committee. The balance between over-soliciting patient advisors and soliciting them just enough can be fragile. Therefore, results identify co-facilitation as a must-have. Otherwise, shared leadership through co-facilitation with a patient advisor could be considered, as it was demonstrated to be a factor contributing to patient engagement in governance.\(^{15}\)

In summary, the engagement process is a collective process. Considering selection, training and coaching activities as such might strengthen the work modalities in partnership.

**The patient partnership culture: the need for “champions”**

ACBPCPs nurture a professional culture, as primary care professionals come to share common experiences and values through the development of their “occupational identity”.\(^{41}\) For organizational change to take place, the collective process must extend beyond the management structure to the rest of the organization, in a dynamic process nourished by interactions between individuals who share a common purpose, a concept reflected in the literature as “learning organization.”\(^{39}\)

A recent review reported different methods that contribute to changing organizational culture, including a top-down approach where managers advocate for patient engagement initiatives, dedicated resources and an educational program.\(^{7}\) Consistent with the literature, findings also demonstrated the importance of the management heads’ support and fundamental role in terms of leadership and vision.\(^{7,13,15}\)

However, in the current case, the impact on the entire organization seems limited or not recognized as such by staff outside the management committee.

Results also find echoes in the literature by suggesting the need for simultaneous local “professional-driven initiatives”\(^{7(p.15)}\) in a concurrent bottom-up approach, through clinical, teaching or research co-construction initiatives.\(^{38,40}\) Partnership in care, patient-oriented research priorities and the integration of patient partnership concepts into the medical curriculum set the table for the management revolution currently taking place. Nevertheless, for co-construction ideas and solutions to translate into practical initiatives in the field, co-construction “champions” at the ACBPCP’s other levels are necessary to vouch for this partnership approach, be initiators of change and attest of changes happening on clinical grounds before the committee, for it to update itself.\(^{38}\)

**Limitations**

This study has three main limitations. First, interviewed participants were in favor of patient engagement in health governance from the outset, so exploration of a contrary point of view was limited. The second limitation concerns the fact that the point of view of professionals from the AEBPCP was possibly underrepresented because of the small number of respondents. This is probably best explained by a lack of availability on the part of the clinicians but may also signal less interest in taking part in this kind of reflection. Lastly, the principal investigator being a colleague of the committee members, a desirability bias could have been present, though the interviews seem to show that participants spoke freely.\(^{32,42}\)
Despite these limitations, to our knowledge, this study is the first to contribute to identifying the challenges to patient advisors’ engagement on an academic management committee and reflecting on an ACBPCP’s organizational culture in terms of patient partnership.

Conclusion

This study provides us with insight on the process of engaging patient advisors on a management committee in an ACBPCP. Several recommendations can be made to improve the current process taking place at the ACBPCP studied and guide other organizations interested in a similar approach:

- Careful patient advisor selection based on specific criteria is essential, but the committee’s non-patient members’ recruitment must also be sensitive to fundamental characteristics, like openness.
- Training should reunite professionals with patient advisors and regular debriefing should be maintained, as an improvement opportunity.
- Co-facilitation is a must have. Inclusion of an external facilitator or co-facilitation with a patient advisor are avenues that should also be considered.
- Several co-construction “champions” from all the ACBPCP’s levels should collaborate and exchange with the management committee in order to diffuse partnership initiatives.

The results of this study will contribute to the writing of a guide on the engagement of patients within ACBPCPs’ governance, as other ACBPCPs in the province of Quebec are already showing interest in implementing patient engagement initiatives at the strategic level of their organization. Finally, further research is necessary in order to compare academic community-based practices whose governance activities take place with or without patient advisors.

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