

Engagement of patient and family advisors in health system redesign in Canada

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Abstract

Objectives: Globally, there has been a shift towards integrated care delivery and patient-centredness in the design of health services. Such a transformation is underway in Ontario, which is progressively using an interprofessional team-based approach known as Ontario Health Teams (OHTs) to deliver care. During their initial development, OHTs were required to integrate patient and families' preferences, experiences and opinions in the form of consultation and partnership with patient and family advisors (PFAs). This study aimed to understand how PFAs were involved in the early stages of planning for health system change and the perceived benefits of including PFAs in system reform.

Methods: This study used a qualitative descriptive design. Semi-structured interviews were conducted with 126 participants at 12 OHTs, including PFA ($n = 16$) and non-PFA ($n = 110$) members (e.g. clinicians). Data were analysed thematically.

Results: We identified four themes; mechanisms of engagement, motivations to engage, challenges to PFA engagement and PFAs' impact and added value. Overall, participants viewed PFA engagement positively and PFAs felt valued and empowered. There remain logistical challenges around PFA compensation, and the amount of time and training expected of PFAs. However, all participants believed that developing an understanding of the patient, caregiver and family experience will strengthen the engagement of PFAs in OHT planning, decisions and policies.

Conclusions: Diverse approaches to and stages of PFA engagement fostered meaningful and highly valued contributions to OHT development. These were considered critical to successfully achieving the mandate of patient-centred care reform.

Keywords

patient and family advisors, co-design, health system design

Introduction

Globally, health systems are constantly trying to improve care to better meet the needs of the patients they serve. This has been addressed through integrated health services to manage and deliver services in a way that ensures patients receive a continuum of health promotion, disease management, rehabilitation and palliative care services.¹ A fundamental pillar to integrated health service delivery is the inclusion of the perspectives of patients, carers and communities.¹ The first of five strategic directions proposed by the World Health Organization to further integrate health service delivery emphasizes 'empowering and engaging of people through providing...opportunity, skills and resources'.^{1(p8)} The idea of patient engagement has been proposed as a potential solution to make the health care system more effective and efficient, and thus patient engagement has become embedded within integrated health services.² Partnering with patients, families and caregivers

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can help health care initiatives consider diverse preferences, leading to improvements that better orient care to meet patient and family needs.^{3,4}

The shift towards incorporating patient-and-family-centred values in health care delivery has increased through various patient and family engagement strategies in health care, representing a shift towards incorporating patient-centred values in health care delivery.⁵ We define patient and family engagement as a partnership of patients, families and health care providers working collaboratively to help improve health care outcomes, across various levels of the health care system.⁶ Areas for patient and family engagement include, but are not limited to, participation in direct care and care at systematic levels (e.g. system reform and quality improvement initiatives), communication of patient demands and transformation of care to protect autonomy of patients.⁷

However, despite the increased attention towards patient and family engagement by researchers, health system administrators and policymakers, there is a little consensus about how to best involve patients and their families. Meaningfully and effectively engaging patients, families and caregivers can be enhanced by understanding engagement in health system change. However, a recent review of patient and family engagement in health care service delivery and design to improve quality of care found that only 25% of studies evaluated the experience of patients throughout the engagement process.³ Understanding how patients and health system actors feel about patient and family engagement experiences, the barriers and facilitators and the motivations that drive participation can provide valuable insights into how to more efficiently implement change, avoid tokenistic involvement and reduce participant burnout.

The Ontario Health Team (OHT) transformation taking place in the province of Ontario, Canada, brings together service providers across the health care continuum to support patients in a more integrated model of care.⁸ OHTs vary in size and composition across the province with the first cohort of applicants consisting of a two-thirds, one-third split between urban/suburban and small community/rural areas, respectively.⁹ Each OHT includes one or more hospitals, primary care organizations, community services providers and some representation from long-term care, mental health, paramedics and other sectors. These integrated networks of health care providers and organizations share resources and co-create a governance structure.¹⁰ OHTs will work together to serve a self-determined defined priority population (for example, the elderly or people with complex needs).¹¹ This population will grow in proceeding years to include all people within a defined geographic region. Previously, within regional structures known as Local Health Integration Networks, funding agencies were separate from delivery organizations, and

patients often reported difficulties with navigating and accessing care between health care settings.¹² In the OHT model of care, funding will follow the patient, such that care is better coordinated and more directly in line with patient needs.¹¹

In 2019, the Ontario government initiated the OHT process by inviting health care providers and organizations to group and assess their readiness to form OHTs. Candidates who demonstrated an ability to meet readiness criteria were invited to submit a full OHT application.¹¹ Applicants were provided with guidance documents, toolkits and resources to help them with OHT design and decision-making.¹¹ Successful applicants were required to collaborate to co-design their OHT with patients and their families, allocate resources and begin OHT implementation.¹¹ Co-design involves meaningfully including patients, families and health care providers in redesigning aspects of health service delivery and, in turn, provides an actionable way of promoting patient-centred care.¹³

At maturity, OHTs are expected to ‘uphold the principles of patient partnership, community engagement and system co-design...[and] meaningfully engage and partner with – and be driven by the needs of – patients, families, caregivers and the communities they serve’.^{11(p11)} Each OHT is permitted to design care delivery to meet the needs of its population and can similarly decide how best to engage patients and families in this process of system design.¹¹ Engagement can occur across a continuum of input and influence, ranging from consultation to equal partnership.⁶ One suggestion given through OHT guidance documents was to include a patient advisor or patient and family advisor (PFA) role.¹¹ While there is a growing body of literature to support the utilization of PFAs across levels of engagement, the actual use of PFAs in practice is not consistent, as documented within the literature. Studies have highlighted challenges to true engagement, including organizational-level support, culture and commitment of resources, PFA motivation, confidence and capabilities, attitudes of professional stakeholders towards patient and family engagement and the availability and mobility of PFAs.^{3,14}

There is a lack of consensus on how to best engage PFAs. Given the possible variation in when and how patients, families and caregivers are involved in each OHT, in this study, we aimed to understand how PFAs were involved in the early stages of planning for health system change. We explored experiences of PFA engagement (through the lenses of PFAs and non-PFAs) during the development of OHTs across the province. As OHTs continue to form, and existing OHTs shift to more permanent decision-making structures, PFA engagement strategies should evolve so they remain fit for purpose.¹¹ At the time of our study, there were 30 OHT applicants. This number is continued to grow to upwards of 100 OHTs. We believe an understanding of

early PFA involvement will support successful implementation and future PFA engagement.

Methods

Study design

We conducted a qualitative descriptive study to gather in-depth information about the experiences of participants involved in the co-design process in the development and implementation of OHTs.¹⁵

Participants

Twelve OHTs (representative across geography and health care sectors) were selected to participate in our research, drawn from the original 30 applicant teams. The sampling of OHTs was random representative/proportional, informed by geography and sectoral leadership (hospital/community leadership and rurality). Four OHTs (27%) were located in a rural context and eight (73%) were led by hospitals (see [Online Supplement S1](#)).

Seven to 15 possible participants (both PFAs and non-PFAs) were recruited from each OHT. These participants were identified by the OHTs themselves as having shaped the formation of the OHT. Non-PFA participants represented a range of clinical (e.g. physicians) and administrative participants (e.g. executive director of a health care organization). PFA participants included patients, family members and family caregivers (ie a relative, partner, friend or neighbour providing assistance to someone with an illness or disability without financial compensation).

Data collection and analysis

Data was collected through semi-structured interviews, lasting approximately 60 minutes. Interviews took place in early 2020 via telephone or video-conferencing software (Zoom). Participants were asked to describe their experience throughout the OHT development. Five trained qualitative researchers coordinated and conducted the interviews. All interviews were audio-recorded, professionally transcribed verbatim and reviewed for accuracy.

We conducted both an inductive and deductive thematic analysis.^{16,17} First, all members of the research team reviewed the data and contributed to a codebook, which was then applied to the transcripts. NVivo 12 was used to organize the data and support the coding process.¹⁸ Next, all authors reviewed the coded data and contributed to theme generation through a series of meetings. To maximize the credibility of the findings, all authors reviewed and agreed on the content within the final themes. In this paper, we report specifically on the findings of interview discussion around PFA engagement ([Online Supplement S2](#)).

Ethics

Ethical approval for this research was obtained through the University of Toronto Research Ethics Board (PROTOCOL# 38072). Participants provided verbal informed consent prior to data collection.

Results

One hundred and twenty-six participants representing 12 OHTs participated in this study ($n = 16$ PFAs and $n = 110$ non-PFAs). Of the PFAs, four were patients (25%), seven were caregivers/family members (44%) and five were both patients and caregivers/family members (31%). Overall, PFA engagement was described as positive by both PFAs and non-PFAs. We identified four themes: (1) mechanisms of engagement, (2) motivations to engage (3) challenges to PFA engagement and (4) PFAs' impact and added value. PFA and non-PFA participants' experiences are combined in the themes and nuanced differences in perspectives between groups are highlighted. We illustrate each theme below using sample quotations. The sources of the quotations are indicated by the participant type (i.e. PFA or non-PFA) and participant ID.

Mechanisms of engagement

Throughout the interviews it was clear that the timeline of the OHT development was rushed. While most interviewees saw this as a major challenge to incorporating PFA engagement, some saw it as a drive to change:

Our sage patient and family advisor said, 'Guys,...the ministry has given you a real opportunity, and it is fast. But use that constraint to actually say, you know, "We could toil away on planning forever but use this as an opportunity to see what we feel we can do quickly."' (Non-PFA, 02_2)

The majority of PFAs were most heavily engaged during the application process of the OHT formation, but some reported being involved prior to that in the readiness assessment phase. Some PFAs were unsure of the timeline or where in the process they were as an OHT. In some cases, given they were only involved in the later stages of OHT development and once some fundamental decisions had already been made, PFAs felt their involvement may have been an afterthought.

Most non-PFA members agreed that PFAs could have been engaged earlier in the process, but thought tight timelines made that challenging to do:

We certainly had patient and family advisor engagements, but I think we could've even had more. It's just that our timelines were so tight that it was, in some ways, it just got hard to

organize that level of consultation. But that would've been one where I would've liked to have seen even more. (Non-PFA, 09_06)

The primary methods used to broadly engage PFAs were focus groups, town halls/community engagement events, open houses and social media groups. Some OHTs engaged PFAs at the same time they engaged other care providers. As one non-PFA recalled:

So they did meetings at the hospital...there were posters everywhere. And just open sessions that you could go to...Ones which were specific to patients and service users, ones that were specific to certain types of health care provider or worker. So, I believe that cleaners had a piece, doctors had a piece, nurses had a piece, social workers had a piece. And they were normally held in a big group-type thing in the hospital. (Non-PFA, 12_1)

Several OHTs took advantage of existing Patient and Family Advisory Council (PFAC) structures within partner organizations to get patients involved in the OHT process. As the development of OHTs progressed, some PFAs were involved as committee members and were given permanent seats within their OHT. Structured forms of engagement for PFAs included seats on councils and representation in working groups (i.e. working groups, and steering, executive and digital health committees). Engagement was further strengthened within some OHTs where PFAs were involved in hiring decisions for positions on the OHT development team. PFAs on those OHTs described their role as part of central leadership. Nearly all PFAs in these positions were those who had previous PFA experience, prior connections or came from within PFA networks in the previous regional health care system.

All participants felt PFA training helped PFAs to engage in OHT work more effectively. Although the duration, availability and comprehension of training varied across OHTs, participants described education sessions as highly valuable for providing information on abbreviations, policy jargon, models of care, as well as funding and structural aspects of OHT work. PFA participants felt more able to engage when they were formally introduced to the various roles within the committees and how the committees functioned.

PFAs were involved in forming and co-leading PFACs and patient advocacy networks. Some were new to OHTs and some had experience. Some PFAs felt upskilled as a result:

It's very, very important to say I had this, you know, experience as a patient caregiver, but also we personally develop, I'd say, strong skills from a business management standpoint, from a

strategic planning standpoint, from a system design standpoint - just based on our background. (PFA, 06_7)

Creating an environment to empower PFAs within the OHT process was an essential step in supporting overall PFA engagement. For example, some participants described how meetings often began with stories of personal patient experiences to help promote storytelling.

Motivations to engage

All PFAs described having a genuine interest in participating in matters related to health care delivery and thought it was important to provide critical insider input in health system reform. Indeed, nearly all PFA participants had firsthand experience of gaps in care:

I lost both my parents. ... And they're all in that age bracket and getting help for them is definitely something that I'm committed to,... There's a lot of good organizations out there, but it is very difficult to navigate, and we found it very difficult navigating that with our families, and especially, you know, when they got released from a hospital, we found that it was very hard to get the care you needed at home, for the appointments. (OHT, 23_9)

Beyond that, there were two common reasons PFA participants gave for engaging with the OHT work. First, the majority had previous involvement in PFA work or sat on PFACs within the regional health system or partner community health centres. In these cases, most often a health administrator had encouraged the PFA to join the OHT initiatives. One PFA recalled:

I guess another thing that helped me be involved and be able to contribute, is the experience I already had with my local hospital's PFAC. I got to understand the world a little bit because I've been involved there for a few years. (PFA, 02_5)

Second, the professional backgrounds of some PFAs influenced their motivation to engage, which included nursing, social work and health management or administration. These PFAs cited previous work experience within the health care system or in patient advocacy networks as an explanation for their increased confidence to meaningfully contribute and engage.

Challenges to PFA engagement

The barrier to meaningful PFA engagement cited most often by both PFA and non-PFA participants was communication challenges. Some PFAs felt frustrated that they were not adequately kept up to date on outcomes, next steps or how their input was incorporated in wider team discussions.

PFAs felt that they often needed to reach out themselves and ‘probe’ to stay informed. PFAs also described a lack of follow-up on aspects of the OHT development they were involved in. For example, one PFA shared that they were not aware of whether their OHT application was accepted and selected to move forward:

I’m sure they have collected everything. But it would have been nice if maybe caregivers were told, ‘This is the outcome’, next steps, and so forth. (PFA, 11_4)

Non-PFAs described challenges in communicating the overall aim and goal of the OHT:

The concept of the Ontario Health Teams, from how we as a system are approaching it versus how it’s seen from a patient/caregiver perspective, is still very challenging to help people really understand how this will make their lives different. (Non-PFA, 09_7)

Some PFAs felt the overuse of health policy jargon, care models and design/business terminology and concepts caused them to feel intimidated or overwhelmed in meetings. To keep up, these PFAs had to do additional research, usually on their own time:

It can be overwhelming for someone like, you know, who hasn’t had the health experience and stuff...It’s a lot of reading and it’s a lot of work...It’s also volunteer. (PFA, 04)

A few PFAs said they only had a limited understanding of how OHTs would create governance models within a complex system. PFAs were aware of the complexity of the health system, combined with the goals for OHTs set out by the Ministry. For some PFAs, finding a model that would work seemed arduous:

The governance part, I would say it’s over my head because I’ve been involved with it, but I can just see that being a big drawback to how this is going to go forward. (PFA, 04_5).

This lack of understanding of jargon and models hindered PFAs’ engagement as many did not have additional time or resources to dedicate to supplementary learning or preparation. To mitigate this, some PFAs described using informal PFA networks to share resources and educational materials across OHTs.

Another challenge for engagement discussed by PFAs was the lack of adequate compensation for items such as travel, parking or to cover additional costs for attending regular meetings.

I’m not sure if there’s been any discussion at other OHT tables about this, but payment of expenses to get to and from

[meetings]. Sometimes you have to take a cab. So there needs to be something in place to cover that transportation cost. (PFA, 06_7)

Non-PFAs acknowledged compensation was a concern for PFA engagement. Whereas some non-PFAs suggested how to standardize an honorarium system across OHTs, other non-PFAs wondered whether engagement should be based on goodwill. While there was no consensus as to whether compensation should be provided, participants suggested the issue should be solved:

We have to look at, do we want to pay an honorarium? One [OHT] can’t do it and the other one not, because we are in so many contiguous ones it would be unfair. So, we have to figure out a way to do that. (Non-PFA, 05_8)

Most PFAs felt that genuine efforts were made by OHT members to keep them engaged and informed on decision-making conversations. However, a few PFAs described a lack of consideration for their involvement and efforts. They felt disconnected with executive committee members when decisions were made without PFA consultation:

There have been a few instances where decisions have been made and there’s been no explanation. (PFA, 06_7)

Lastly, the tight timelines were seen by some to be a barrier to PFA engagement. PFA and non-PFAs described feeling an unnecessarily increased sense of urgency to meet tight timelines, particularly in the summer.

I think people were, you know, over-trying to achieve such tight timelines over the, essentially, month of August...A lot of cycling out on various vacations and things like that to drive big decisions, [which] is really tough and a bit daunting. (Non-PFA, 02_2)

PFAs’ impact and added value

PFAs believed they brought value to the OHT development process by sharing important perspectives, clarifying misconceptions, contributing skillsets and validating the process. PFAs said they brought personalized stories and narratives that captured the nuances of patient care experiences. Many PFAs felt that telling their story would make services better for others:

I think I was able to bring my lived experience and my own way of navigating through the health care system to make improvements, make it better. (PFA, 04_5)

They described feeling valued and empowered throughout the OHTs’ development process:

As a matter of fact, I am quoted in our proposal a couple of times about some of the things that I'd said. (PFA, 03_2)

OHT participation had an overall positive impact on PFAs. They felt empowered to gain a deeper understanding of the complex structure of the health care system and to develop new relevant skills. Some PFAs contributed to system design and service delivery aspects, leaning on their professional expertise (i.e. business management and customer/client service backgrounds). This led some PFAs to work directly with organizational leadership, attending municipal council meetings and town halls where they presented aspects of PFA engagement in the OHT initiative and outlined the importance of addressing the needs of the community and including the opinions of patients.

The majority of non-PFAs perceived PFA engagement as positive, active and helpful in the OHT development process. The engagement of PFAs gave non-PFAs pride in the process, due to the importance placed on patient and family voices. Non-PFA participants perceived strong PFA engagement and valuable partnership amongst all team members, citing examples of PFA voting rights, accountability and leadership roles. Some felt that PFAs went above and beyond the call of duty by sharing interesting reading materials (such as policy briefs, FAQs and training documents) and posing critical, challenging and productive questions during and outside meetings. Non-PFAs talked about PFAs identifying gaps and areas for improvement in the OHT model, putting forth challenging, out-of-the-box questions and giving regular constructive criticism.

Both PFAs and non-PFAs acknowledged the valuable role PFAs had in redirecting conversations back to the fundamental goal of OHTs (to provide patient-centred care) whenever meetings or discussions veered off track or when non-PFA members began prioritizing other aspects of the process, including funding, profits and cost-benefit analysis. As one PFA explained:

As a patient and caregiver I feel sometimes we have a little bit more freedom to ask those difficult questions and to push the issue, because we're not organizations who are going for funding or who are trying to fit into the current model. (PFA, 10_9)

Discussion

This study explored the experience of PFA engagement during the process of co-designing a health reform effort in Ontario from PFA and non-PFA perspectives. As a new model of integrated care, very little research has been published on OHTs; however, we had a unique opportunity to learn from newly developing models and to explore actual experiences.¹⁹ We were able to identify aspects of engagement that may promote more efficient and positive

engagement experiences, as well as several challenges and barriers system reformers may want to mitigate.

Resistant or negative attitudes from professional stakeholders can present a major barrier to effective patient and family engagement.^{3,20} In OHTs, non-PFA stakeholders held very positive attitudes towards the PFAs' involvement. This contributed to the PFAs feeling valued and influential.^{3,14} Overall, the PFA narrative was very positive, with both PFAs and non-PFAs identifying tangible impacts that PFAs had on the co-design process. PFAs were passionate and dedicated to the OHT process and maintained the teams' focus on patient-centred values. Engagement of PFAs gave non-PFAs pride and led to the belief that patient voices were fundamental to the process of OHT development. Both groups remained enthusiastic about current and future involvement of patients, families and caregivers within the OHTs' communities.

The enthusiasm of PFAs and non-PFAs helped to create and augment an 'engagement-capable' environment.²¹ Engagement-capable environments have three core processes: (1) enlisting and preparing patients, (2) engaging staff to involve patients, and (3) ensuring leadership support and strategic focus.²¹ Our results echoed these processes and brought to light four important considerations required to sustain engagement-capable environments within health systems reform. First, participants highlighted that meaningful patient engagement would take time and deliberate effort. The OHT development process was rushed (it had a tight summer timeline); however, some OHTs managed to engage PFAs effectively despite this timeline. In these instances, OHTs used inclusive training, sharing opportunities, voting rights and considerations for compensation, which contributed to increased feelings of value and engagement levels. In other OHTs, engagement felt less meaningful, often a result of PFA involvement at stages later than were ideal. The absence of such a plan has been commonly recognized as a barrier to participation and a reason some organizations prefer to avoid engaging patients.²²

Second, selecting the patients to be engaged in an OHT is a complex process that often required revisiting and adjusting throughout OHT development. PFAs reported an intersection of experiences and skill sets that motivated them to join the OHT process. A large proportion of PFAs had experience working in the health care or business sector, which contributed to their motivation to volunteer, but also seemed to act as a facilitator to OHT development. Well-trained and knowledgeable PFAs felt comfortable in the OHT environment and possessed an improved understanding of the constraints and limits of the system (funding, resources and time).

The literature suggests that the more a patient partner is trained or becomes integrated into the professional process or system, the less representative they become of the

average lay patient and the less likely they are to challenge the system.^{23,24} While this has been attributed to an increased understanding of how and why the system works the way it does, leading to contributions that are seen as more suitable or agreeable,²⁵ it may also lead patients to feel they are not being adequately represented. Multiple authors suggest balancing this trade-off by engaging two levels of participants: one that interacts with the team more frequently and a second that is consulted in larger groups and less frequently – an aspect of patient engagement that many OHTs employed.^{23,24,26}

Third, feeling valued is essential for sustained engagement. The lack of adequate compensation for PFAs who typically volunteer their time, in comparison to non-PFAs who tend to engage as part of their paid employment, can exacerbate an *us versus them* divide.^{27,28} Compensating participants can make them feel more valued and legitimized,³ as well as increase diversity of opinions from those who cannot afford to dedicate their time or travel due to financial or mobility barriers.⁶

Fourth, creating a formalized structure for PFAs to share knowledge and experiences amongst each other can support engagement. The concept of communities of practice²⁹ may be applied in supporting PFA engagement. While PFAs received training to help them understand health system jargon and meeting processes, some still reported feeling underprepared and requiring extra time to keep up. Resources and educational materials were shared between some PFAs from other OHTs within networks created among themselves. Formalizing this network may not only save time and resources but it also could support and improve PFA engagement.¹⁹ In addition, engagement of a mix of ‘expert’ PFAs and ‘new’ PFAs should be encouraged to ensure diversity in perspectives.^{23(pS10)}

Throughout the development process, OHT guidance has stressed the importance of community engagement.³⁰ Kimminau et al.²⁶ distinguish community engagement and patient engagement by their generalizability: community engagement centres around the principle of representing the views and needs of the larger community in general, while patient engagement tends to focus on and facilitate individual stories and experiences within the system that are personal and thus less generalizable.²³ Our findings suggest that patient and family engagement can foster and enhance community engagement by gathering patient views through a variety of forms of engagement. In this way, OHTs may be able to encourage community engagement, while upholding the principles of patient and family engagement. For example, the sharing of personal stories and experiences was found to strengthen the impact of PFAs and was appreciated by both PFAs and non-PFAs.

Incorporating broader and more diverse PFAs into OHTs may help further support community engagement.

Furthermore, consultative engagement strategies, such as hosting community town halls led by those currently engaged in OHT patient and family engagement, can ensure diverse populations can give input to OHTs. Being able to include more and diverse voices, while still having greater involvement from a small number of PFAs, can better represent the diverse population served by OHTs.

Limitations

This research had four main limitations. First, interviews were collected from a limited sample of participants and OHTs. As such, our interviews cannot be representative of the diversity of all OHT applicants.

Second, this study captured OHT collaboration at only one point in time. OHTs and their roles are constantly evolving throughout the formation and implementation processes. This means participants’ responses and perceptions of PFAs may change.

Third, social desirability bias may have influenced participants to highlight positive perceptions of the partnership. This is particularly the case for non-PFAs, given that the initiative is heavily patient-centred, and the desirability of patient voices is heavily emphasized in the OHT model.

Fourth, PFAs did not distinguish between the variety of methods by which they were individually engaged. Since PFAs were not involved in the same way across OHTs, it is difficult to determine how PFA factors (such as background, motivation and training) informed the OHT development. This makes it difficult to weigh the facilitators and barriers against each other. For instance, receiving training to help with jargon was identified as a facilitator in one OHT, while another PFA identified insufficient training as a barrier. Hence, a more detailed understanding of what level of training and engagement each PFA experienced may have allowed us to better identify the balance required in such activities.

Conclusion

The implementation of OHTs reflects a common health system trend around the world: a shift to more integrated care delivery with a focus on patient-centredness. With this shift, it is important to understand and prioritize the continued and sustained engagement of PFAs.

To determine methods that effectively incorporate the patient perspective in health care reforms, further research is needed to consider the outcomes related to changes in health care processes, services and the changing relationships between providers and patients. More rigorous evaluation is needed to link these engagement methods with patient outcomes and cost effectiveness.^{31,32}

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Ethics statement

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Supplemental Material

Supplemental material for this article is available online.

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