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Aleisha Fernandes
Ottawa Hospital Research Institute
Grace Fox
Ottawa Hospital Research Institute
Ulyana Osorio
Ottawa Hospital
Holly North Ellingwood
Carleton University
Jacinthe Bisson
Ottawa Hospital
Patricia Pottie
Cancer Care Ontario
Debra Turnbull
Patient Advisors Network (PAN)
Stuart G. Nicholls
snicholls@ohri.ca

Ottawa Hospital Research Institute

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Researchers' experiences in finding patient partners for health research: a qualitative study

Aleisha Fernandes[1], Grace Fox[1], Ulyana Osorio[2*], Holly North Ellingwood[3, 4*], Jacinthe Bisson[*5], Patricia Pottie[5, 6, 7*], Debra Turnbull[8, 9*], Stuart G. Nicholls[10, 11]

1. Office for Patient Engagement in Research Activities (OPERA), Ottawa Methods Centre, Ottawa Hospital Research Institute, Ottawa, Ontario, Canada
2. Patient and Family Engagement Lead at The Ottawa Hospital, Ontario, Canada
3. Department of Law, Carleton University, Ottawa, Ontario, Canada
4. Department of Psychology, Carleton University, Ottawa, Ontario, Canada
5. Patient Partner, The Ottawa Hospital, Ottawa, Ontario, Canada
6. OH-CCO (Cancer Care Ontario), Toronto, Ontario, Canada
7. CACHE, University of Toronto, Toronto, Ontario, Canada
8. Ottawa OHT-ÉSO, Ontario, Canada
9. Patient Advisors Network (PAN), Ontario, Canada
10. Methodological and Implementation Research (MIR), Ottawa Hospital Research Institute, Ottawa, Ontario, Canada
11. University of Ottawa, School of Epidemiology and Public Health, Ottawa, Ontario, Canada

*contributed equally

Correspondence should be addressed to Stuart G. Nicholls, PhD, Centre for Practice-Changing Research, The Ottawa Hospital - General Campus, 501 Smyth Road, Ottawa, ON K1H 8L6, ON, K1H 8L6 Canada. E-mail: snicholls@ohri.ca

Keywords: patient and public involvement; patient partners; advertisement; patient engagement; health research; recruitment; identify

Abstract

Background

Researchers are increasingly incorporating patient engagement into their research projects as more funding agencies make patient engagement a requirement in grant applications. However, there is a noticeable gap in guidance for how researchers can find patient partners to partner with. This was a qualitative study looking at matching systems that link researchers with patient partners for the purpose of patient engagement.

Methods

In this analysis we report on the findings from semi-structured interviews conducted with 19 researchers examining their strategies to find patients to be partners in their research, and the factors that inform this. Data was analysed thematically by dual coders using constant comparative analysis.

Results

Interviewees identified the following mechanisms that they used to find patient partners: personal connections, health system recruitment, partnering with other organizations, matching systems, social marketing, targeted recruitment and previous research study participants. Most interviewees mentioned that they used multiple strategies with varying successes and sentiments. The factors that influenced which strategy they used were based on external (awareness/access to patients, privacy concerns, convenience and timelines) and internal factors (researcher characteristics, patient characteristics and climate).

Conclusion

These results identify methods of patient partner identification and recruitment not previously mentioned in existing research (such as targeted recruitment). It also provides additional considerations researchers use to guide their recruitment strategy for finding patient partners.

Future research may seek to explore how researchers can find and select patient partners more equitably through the creation of guidance targeting factors detailed (such as risk of coercion from clinician-scientists recruiting their patients). Additionally, there is a need explore patient partners' perspective in the changing engagement space as well as how to better support patient partners in finding research teams to partner with.

Plain Language Summary

Researchers are increasingly incorporating patient engagement into their research projects as more funding agencies make engagement a requirement in grant applications. However, there is a noticeable gap in guidance for how researchers can find patient partners to partner with. In this study we interviewed researchers from various backgrounds at the Ottawa Hospital Research Institute concerning their current strategies to find patients to be partners in their research and advocacy work. The main ways researchers partnered with patients were personal connections, health system recruitment, partnering with other organizations, matching systems, social marketing, targeted recruitment and previous research study participants. The factors that influenced which strategy researchers used were awareness/access to patients, privacy concerns, convenience and timelines, as well as researcher characteristics, patient characteristics and climate. Future research may seek to explore patient partners' perspectives about how they find engagement opportunities as well as how to find and select patient partners in a more equitable manner.

Background

Patient engagement is the conduct of research with patients (individuals with lived experience including informal caregivers, family and friends) occupying a role of active collaborator or partner, rather than as a study participant (1). In this capacity, they are involved in shaping the design or delivery of research. Patient engagement is now embedded within various reporting guidelines, as well as the updated Declaration of Helsinki which outlines ethical principles that underpin research (2–4). As the expectation for patient engagement in research has grown, so has the need for resources and materials to support both patient partners and researchers. One particular area of need identified is guidance concerning the initial linking of researchers and patient partners and specifically, the ethical and practical issues around the identification and selection of patient partners for research (5,6).

Previous systematic reviews have found great variation in methods employed by researchers when identifying patients with whom to partner (6–8). Studies mentioned included word of mouth, partner organizations, previous study participants, use of clinics and personal contacts (7). However, due to poor reporting by studies reviewed, there was minimal information often provided concerning additional considerations taken for the recruitment of patient partners. A recent survey of researchers by Landers et al., explored current recruitment strategies and additional considerations for recruitment. They found that researchers reported that finding patient partners was often very difficult, with many reporting they reuse patient partners or rely on word of mouth to find patient partners. However, many noted that there were different considerations that need to be considered when choosing patient partners such as the project objectives and the aim of the patient engagement strategy and reported practices varied for the recruitment of patients compared with the public (9). Similarly, Woolf et al described how

patient partners are recruited within the context of a collaborative learning health system (10). From their interviews, they mapped consequences of recruitment practices, such as reduced diversity and missing perspectives when recruiting primarily through medical providers. However, they detailed more equitable methods required more resources to allow for more thorough recruitment and selection processes which may not be ideal for researchers working on tight timelines. Despite these studies, what has largely been missing is detailed evaluation of the underlying reasons why researchers have adopted different approaches to recruitment. In one of the few studies to consider this, Vat et al. found that researchers' decision for strategies were often influenced by the researchers' environment and patient characteristics (11). However, there was minimal analysis provided concerning factors that are specific to researchers' decision of strategy chosen and minimal studies conducted more recently to examine this topic.

Given the ongoing commitment to patient engagement, resources being invested, and current lack of information about when or how different approaches to recruitment may be employed, there is a need to examine the opportunities and challenges for the recruitment of patient partners. To further research in this area, we conducted an in-depth exploration of current recruitment practices used by researchers, as well as factors that impact researchers' preferences for certain approaches.

METHODS

We undertook a qualitative study consisting of focus groups and interviews with the goal of identifying key considerations for the development of a matching system that could connect researchers and patient partners in research. In the present manuscript we report on interviews conducted with researchers and part of the discussion, in which we explored how they currently

identify and recruit their patient partners and their reflections on these approaches. The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of the Ottawa Health Science Network Research Ethics Board/ Conseil d'éthique de la recherche du Réseau des sciences de la santé d'Ottawa 20230321-01H. Clinical trial number: not applicable.

Study Design

For the purpose of this study, recruitment strategies were defined as methods researchers have used to find patients to engage with, in a partner capacity (not as a study participant) on a health research project. We also investigated the factors that may impact researchers' choice of strategy. Our overall study design was informed by an environmental scan of the literature as well as meetings with our Lived Experience Advisory Group (LEAG) who were collaborators throughout. This allowed for our study to gather information concerning methods as well as researchers' sentiments and perspectives regarding different approaches. This project was also conducted based on a need identified by patient and system partners at The Ottawa Hospital.

Sampling and Recruitment

Individuals were eligible to participate in if they were members of a research team that have worked with patient partners. This included principal investigators, but also research staff such as research coordinators or research associates who may have more direct operational roles within the study. Due to a lack of sampling frame for research staff, research team members were identified through senior researchers (usually the principal investigator occupying a Scientist

position. Identified researchers could then participate themselves and/or forward the invitation to a member of their research staff (e.g., research assistant, research coordinator).

Researchers at the Ottawa Hospital Research Institute (OHRI) were purposively sampled based on clinical area and career stage, and, where possible, extent to which they have engaged patients in research. This allowed for a variety of experiences to be captured including those who had not accessed institutional supports for patient engagement at the OHRI. Researchers were identified through:

(a) Existing tracking mechanisms operated by the Patient and Family Engagement Program at The Ottawa Hospital, which maintains records of request for patient advisors

(b) e-Notice of Intent to apply to a grant, which includes information regarding the engagement of patients during a project (12), and

(c) Service request records to the Ottawa Methods Centre requesting support for patient engagement,

(d) Public records detailing established patient engagement practices (e.g. institutional web pages, publications, etc.).

Data collection

Interview questions were developed by the research team and were piloted with members of the research team. The full interview guide and consent forms can be found in Supplementary File 1. Interviews were conducted, recorded and transcribed with consent using Microsoft Teams by two interviewers (GF and SN). Transcripts were reviewed afterwards for transcription verification as well as deidentification of individuals through removal of all personal identifiers.

The primary outcomes of interests were current strategies of recruitment used by researchers to identify patient partners, as well as the factors that may impact their choice of recruitment strategy.

Data Analysis

Transcripts were analysed using NVivo 15 and 12 (QSR International) and followed a thematic analysis approach (13,14). The results were analyzed with a mix of inductive and deductive analysis. To increase credibility and quality of analysis, dual coding was conducted where two coders independently analyzed all transcripts (AF and SN) and then met to review and discuss coding discrepancies. Following initial open coding one reviewer (AF) undertook a process of data reduction to bring the initial codes together as part of broader themes/constructs that was guided by an existing conceptual model crafted by Vat et al. and in line with constant comparative methodology (11,15). This was reviewed by a second reviewer (SN) and modified based on feedback. The refined model was presented to the LEAG for feedback and further refinement. Analysis occurred May 2024 to January 2026.

Patient Involvement

Members of the LEAG were composed of individuals with experience being patient partners at The Ottawa Hospital in various capacities. They helped inform the overall study design and approaches to recruitment, the content of the interview and focus, as well as providing reflections on the results. One of the members of the LEAG attended a focus group as an observer and provided further insight into the results afterwards. Members of the LEAG attended regular

meetings and were offered an honorarium for their time. More details can be found in Supplementary File 2.

Reflexivity Statement

As researchers and patient partners immersed in the field of patient engagement and who have utilized various routes of recruitment, we strived for a non-biased approach to the analysis and conduct of the interviews. We had an interview guide that was co-created a-priori with our lived experience advisory group and was based on an environmental scan of the literature. Prior to analysis, the interview transcripts were reviewed to have all identifying information removed and we employed dual coding to reduce the influence of our personal biases in the analysis. One of the coders (AF) also had no role in the interviews and was able to analyze the data blind, which further reduced potential biases from prior relationships members of the research team had with the interviewees.

Results

Semi-structured interviews were conducted virtually between October 3, 2023, and May 14, 2024, and ranged between 20 and 60 minutes. All identified researchers accepted invitation and participated. A total of 19 researchers were included with 12 being clinical researchers, 4 being methodologists, and 3 being a mixture of both clinical and methodology focussed researchers. All interviewees had varying years of experience of patient engagement, and many reported using a combination of different approaches. Two major themes were identified: 1) recruitment strategies for finding patient partners; and 2) factors that influence choice of recruitment strategies used.

Recruitment Strategies

Researchers reported using various strategies with varying success and sentiments. These strategies also varied based on the research topic and required perspectives and skills for the patient engagement opportunity. Approaches included the use of personal connections, recruitment from healthcare institutions, partnering with organisations, the use of formal matching systems, social marketing, targeted recruitment of known individuals, and the recruitment of previous research study participants.

The use of personal connections: This approach included connections that are facilitated by other researchers through work-related interactions but could also be based on personal connections. Researchers noted that they would reach out to their social network to find other researchers, colleagues or current patient partners on the team who may know someone or who can help share the opportunity to their personal networks. A strength of this approach was an implicit validation – the person making the connection was vouching for the person they were putting forward. In addition, the personal connection approach was often deemed more efficient when contrasted with broader approaches that failed to yield suitable candidates despite requiring more time:

> *"I think to me the better or more effective strategy may be trying to use like a snowball sampling where you actually have identified or [are] trying to find a champion […] So, like a few of our partners even say that or do let me know if you need more patient partners, I can connect you. I can find more for you. So, I think*

with that commitment and with like those kind of champions, it's more effective" (Interview 2, Methods Researcher).

Recruitment from health system: Another route identified by clinician scientists was that they, or their clinician colleagues, would identify potential patient partners based on their clinical interactions. Examples included clinician scientists having research coordinator shadow them during clinical visits to help identify potential patient partners or to survey the demographics of patients they interact with and identify patient partners based on the results. One interviewee mentioned that they took notes about patients that said they would be interested in getting involved in research in the future:

> *"Very commonly it's my patients who are saying what can I do to help?... They're often very, very kind and grateful and want to help in some way, volunteer or whatever. And so occasionally where I will have these issues or like someone has an unusual situation and you'll say, well interestingly we've got a bit of a research program in the problem that you have and often they're super keen to participate.... and they're usually very, very engaged."* (Interview 4, clinical researcher**).**

Partnering with other organizations: This approach included contacting organizations dedicated to certain health conditions and who have a large number of volunteers/employees with lived experience of the health condition as well as organizations that have established patient partner advisory groups with expertise on relevant topics. As one researcher noted:

> *"They're aware of many patients and they collect stories. And so sometimes I've turned to them to say, do you have a patient who could speak about this? But it's also who you know…will communicate effectively? Who you know is comfortable with a media interview or telling their story in public"* (Interview 5, Clinical Researcher).

A noted benefit of this approach was that it helped facilitate access to a patient population when researchers did not have immediate access to them. How researchers connected with organization varied, with some being connected by patient partners, funders, other researchers, or initiatives not related to research (e.g. fundraising or advocacy initiative). Another notable benefit was that patient partners from organizations often brought multiple perspectives from their connections inside the partner organization. They may have also had training in patient engagement and/or research.

***The use of formal matching Systems*:** This included using institutional processes and supports (such as connecting with the Patient and Family Engagement Program at the OHRI) or through other organizations with established matching processes that link researchers with patient partners. These may be web-based and vary in terms of the degree of staff support provided.

> *"And so the way that we identified patient partners for that project was we put together an advertisement which was done again with [OHRI's] help... So that was really easy. We simply prepared the advertisement. It was distributed to the patient partners and whoever was interested"* (Interview 8, Methods researcher**).**

Social marketing: This included marketing that was displayed where the target population naturally gathered. Examples included working with organizations to distribute advertisements to online and in-person community spaces, as well as within clinical settings.

> *"I don't believe I was ever clinically involved with her, but her involvement with us came through posters that we had placed in in various clinics looking for people with lived experience to participate or to contribute to a research program and so her involvement with us came from there I guess"* (Interview 7, Clinical Researcher).

A reported advantage of this approach was the advertisements didn't require immediate direct interaction and could help mitigate potential patient/physician power dynamics that can make recruitment from personal clinics coercive. However, a challenge of this approach was the potential for many responses for a limited number of opportunities, thus potentially creating additional workload and discomfort from turning away patient partners. As one interviewee noted.

> *"The [FOUNDATION] put a call using social media.... We were hoping to get 10 people with lived experience to participate in a more constructive way and, I don't know if backfired is the right word, but within about 3 days or four days we had 400 and it was overwhelming"* (Interview 7, Clinical Researcher).

Targeted recruitment of known individuals: Researchers also discussed intentional recruitment of individuals without prior relationship. These individuals were identified based on their

advocacy work and openness about their lived experience with a health condition. For example, an interviewee mentioned that they recruited someone who relayed their lived experience as part of a communications piece released by the hospital. Despite having no connections with the individual, they reached out to them and asked if they would be interested in partnering with the research team.

> *"Our 4th member... is someone again that we solicited... from the Ottawa Hospital indirectly... whose story was featured in various communications throughout the hospital. And we thought, oh, wow. And so, we reached out to this individual and said we're actually working in this space. do you have any interest in lending your perspective? And so she did. And has been an active member as well in our team"* (Interview 7, Clinical Researcher).

Previous research study participants: In addition to identifying patient partners through their clinics, researchers also discussed recruitment of patient partners who had been previous study participants. For example, an interviewee mentioned that in one case they had received news that a complaint was filed with the research ethics board. The interviewee followed up with the complaint and found that the complainant had filed it because they wanted to provide feedback about the data collection tools being used. Based on that conversation, they decided to work with the family on the study and future trials to make sure that the patient perspective is brought into the design earlier.

> *"They were really just trying to provide some sort of feedback, and it ended up being a really informative discussion from a very eloquent and well-spoken family that really resonated with me. And then it was like this aha moment of this is what we need to do and try and better understand the outcomes that we're measuring [IN CLINICAL AREA]... I reached back out to this family and said listen, I really would like to develop this. Are you interested in being a member of our team and both she and her mom came on board and became our first patient partners in developing this program and to this day continue to work with us"* (Interview 7, Clinical Researcher).

Factors that influence strategies for recruitment and selection of patient partners

The choice of approach was influenced by past experiences as well as anecdotal information researchers heard from coworkers concerning successes with certain strategies over others. When discussing their recruitment approaches, researchers described several factors that influenced their choice of approach, and which were grouped into 2 main themes: external/imposed and internal factors (further divided into researcher characteristics, patient characteristics and climate). A conceptual framework for the interrelationship of the identified factors can be found in Figure 1.

External Factors: The context of the need for patient partners also influenced the strategies that researchers used, with environmental factors including the availability of different approaches (or researchers' awareness of them), privacy constraints, convenience, the timeliness of the approach or researcher timelines, and the diversity of perspectives that could be obtained. The

availability and awareness of various recruitment approaches restricted available options. For example, although there is existing infrastructure at the OHRI, researchers reported not using it because of lack of awareness and some reported they used it because they didn't have many options available to them.

> *"I remember when I first started, I don't really know where to go... If you have that mechanism ready, it would be definitely helpful for like a newbie like myself, and even for those who have a lot of experience. There's not an easy way for us to try to find someone who'll be part of the team"* (Interview 2, Methods Researcher).

Another contextual factor was privacy constraints of the strategy chosen. An interviewee mentioned concerns about privacy and worries of competitors getting information from platforms. For example, advertising opportunities to partner on grant applications, or prior to receipt of a grant, may risk other individuals copying researchers' ideas if the advertisement is going in a public space. These were allayed potentially through recruitment via personal connections compared to other strategies such as social marketing.

> *"Personally, I think there are some aspects of certain projects that are proprietary, right? Some things... that aren't supposed to be public... I think advertising in the general way is just fine. Like you know, we're... studying acute leukemia and biomarkers... I think that… there are certain things about that, you wouldn't want to be public… especially in this kind of form. So how do I know that this isn't the same group that my competitor is gonna be recruiting from. And then there's patients.*

They already checked in with my team, but now they went to the competitors' team and now they know something" (Interview 3, Clinical Researcher).

Other contextual factors included convenience; interviewees noted how approaches that were mediated potentially alleviated some of the workload on them. For this reason, partner organizations or matching systems that had a staff member that would work with researchers to find patient partners were beneficial when workload was a concern. One researcher mentioned that working with partner organizations meant that patient partners would have some education as well as experience with engagement, further saving on training. Timeliness was also another factor that weighed into decisions, with researchers who are on condensed timelines favouring recruitment strategies that allowed faster turnaround.

Internal Factors: Internal factors were further subdivided into 3 factors: researcher characteristics, patient characteristics and climate of working relationship. The nature of researcher characteristics shaped the ideal patient partner they sought as well as the strategies they felt comfortable using. Strategy choice was also impacted by the potential climate or working relationship that might manifest based on previous experiences, anecdotal stories heard from others or assumptions.

Researchers' own characteristics, including their research area, comfort level and, as well as their knowledge or perceived skills in engagement, were influential in the strategy they chose. For example, their topic of research or area of expertise not only shaped the type of skills and experience that was needed for their project, but also their recruitment strategy. Researchers with

a clinical research focus, and who were clinicians as well, could recruit through their personal clinics. Although, those who did not have ready access to their study population also noted they often looked at alternative methods of recruitment instead of personal clinics. For example, a specialist wanting to see how patients are referred to them only has access to people referred to them and not the people who did not receive a referral or are still in the process of obtaining a referral. Methodologists – who may not need specific lived experience of a disease and may not be clinicians themselves – indicated a reliance on others, such as through personal connections or existing matching infrastructure, to find patient partners.

> ***"****I don't have like a disease content. Well, I do have some, but like most of the time, it's very diverse...So it's harder for me...By using [MATCHING SYSTEM] it's actually allowed me to have like diverse access to more diverse patients".* (Interview 2, Methods Researcher)

Researchers also noted that their own comfort in recruiting patient partners and conducting patient engagement influenced their recruitment approach. Researchers who were less comfortable selecting and engaging with patients indicated a preference for approaches, such as matching systems, with staff to support engagement. Conversely, those researchers who were more comfortable talking to and interacting with patients appeared to be less concerned about recruitment and engagement.

> ***"****I really find that one of the most challenging pieces is if it's somebody brand new, who doesn't already have a track record, you don't know anything about them. I'm*

not really comfortable interviewing them, and then perhaps potentially turning them down because I don't feel that I work well with them. That's so uncomfortable. It's so awkward. I can easily do that with students… but with members of the public, especially if they are just volunteering to help you with the project, how do you turn down a volunteer right?" (Interview 8, Methods Researcher)

As indicated above, the researchers' areas of interest may shape the lived experience and representation they sought which may influence their recruitment approach. Researchers also noted the diversity of those who would be accessible from certain recruitment strategies. For example, through a local matching system, people might be limited to a geographic area, compared to reaching out to national partner organizations that have a broader reach. Additionally, where patients are in their health journey was also a factor that researchers considered to ensure patients' readiness for engagement, as well as how recent or relevant their experience is.

"I think there's a lot of issues around the timing of when the experience is…, sometimes people are always facing healthcare decisions and so another decision or another time will come up.... But I think the issue for me if I was to go to that is I don't want someone who had cancer 20 years ago volunteering as a patient partner on my current cancer symptom management project. And I'm not sure that many on chemotherapy would volunteer to come on my project. Maybe a family member might, but most of the time they're all overwhelmed with what's going on. And so anyway, I think we need to be careful about the

timing of the experience in relation to the volunteer activity." (Interview 13, Clinical /Methods Researcher)

Engagement experience and knowledge from previous work, such as a research or science background, could also help the research study and reduce the time spent onboarding new patient partners or benefit the project. For example, having lab experience is a desirable trait for preclinical engagement. It was also noted that individuals that were well-connected and had prior engagement experience could assist in the recruitment of additional patient partners and potentially assist in recruitment of study participants.

"It was definitely a lot less work for [health condition] with [national organization] because they already had a group of people and they're like, oh, we should connect with these people and they kind of primed us. I think that was definitely very useful and they already had a good sense of what patient engagement was as well too, because I think part of it is like in the past at least it has been finding patients, but then also educating them as to what do we do, what is this about, and what patient engagement is. They did a lot of that in the background, which is very useful. Plus, they have a lot of senior people there like [patient partner name], like senior meaning that they've had a lot of experience in patient engagement" (Interview 19, Clinical /Methods Researcher)

Interviewees also mentioned concerns about working relationships with patient partners who were also under their clinical care. This discussion reflected the potential for difficulties

navigating the power dynamic of healthcare provider and patient in research partnerships and potential for coercion because of it as patients may not feel like they can say no to their healthcare provider. One approach to navigate this was to use a research staff member or colleague to approach people under their care.

> *"The challenge I find is that there's some ethical dilemma because I'm their physician, I'm treating them at the same time, I'm asking them to be a research partner, so that part I did not feel very comfortable with. I tried to mitigate that by asking a research coordinator for the study to be the one who approached the patient, but then the coordinator will mention my name"* (Interview 17, Clinical Researcher).

Conversely, researchers reported that previous personal interaction made them apprehensive of recruiting individuals from certain partner organizations. Researchers reported that when patient partners or organizational mandates were focused on a certain objective, it could be combative and less conducive to a shared research agenda when researchers' and patient partners' goals don't align.

> *"I think at times, especially with the bigger group that we've collaborated with, there have been a few of those really, really quite overbearing patient advocates and they can come off at times as a little bit insulting to researchers or clinicians like because they, you know, they may say, well, you don't care about like the patient perspective, not that they've said*

that to me personally, but just in general like toward researchers or clinicians, which obviously is not true." (Interview 4, Clinical Researcher).

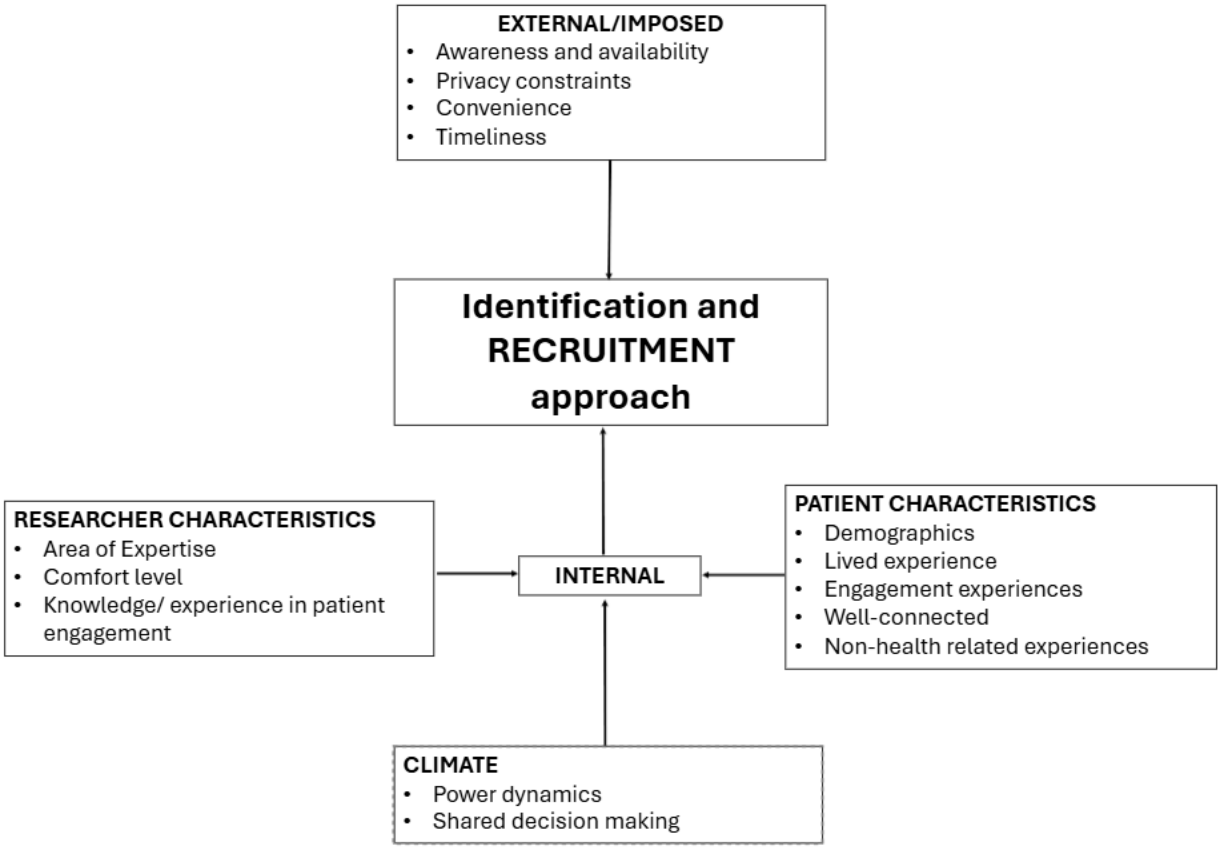


Figure 1. Conceptual framework for recruiting patient partners (figure modified from Vat et al. (2017))

Discussion

In the present study, we interviewed 19 individuals who had conducted patient engagement at the OHRI. The identified strategies used to recruit patient partners were personal connections, health system recruitment, partnering with other organizations, matching systems, social marketing, targeted recruitment and previous research study participants. The choice of strategy was based

on various external and internal factors and the different approaches had various strengths and drawbacks. For example, health system recruitment by clinician-scientists, was considered efficient due to access and convenience but presented ethical concerns due to the potential of power dynamics of the clinician -patient relationship influencing the patients' willingness to critically engage on projects as a partner. Methods that were mediated (such as through partner organization and the internal OHRI matching system) provided options for individuals who did not have ready access to potential patient partners through the health system and potentially offered convenience (due to saved time from filtering applications and training) while avoiding potential ethical concerns regarding exiting power in more direct recruitment methods. It also avoided potential ethical concerns of more direct recruitment methods (such as health system recruitment). Strategies also had trade-offs such as diversity of patient partner pool and how quickly researchers were able to find patient partners. While several approaches have been reported previously (11), targeted recruitment and recruitment of individuals unknown to study teams had not been previously reported in literature.

Targeted recruitment was a new approach identified in our study which may be due to the growth of influencing culture and patient advocates having more social media presence (16–19). There has also been a recent move in research to incorporate more alternative methods to knowledge dissemination that go beyond traditional academic publications to reach a wider audience including through media communications and social media (20). These changes have also been coupled with an increase in more patient-led spaces such as PxP, Involve Canada and Patient Advisors Network that provide supports for patient partners, advertise opportunities and lead their own initiatives (17,21–23). With the growing advocacy work of patient advocates, there is a

need to explore how patient partners are taking on more initiative in finding and creating opportunities as well as how to better connect patient partners with research opportunities.

While the recruitment of previous study participants has been identified in previous studies (7), there remains limited available guidance in terms of how to ethically and practically implement this approach. While this may include participants of concluded studies, it also leaves open the potential for patients to partner on studies for which they have been participants. Indeed, there are examples and guidance in the context of clinical trials where active trial participants have informed elements of the trial conduct and improved the conduct of studies (24–27). Despite this, a recent ethical analysis by Gelinas et al., argued that investigators should be careful in situations where patient partners also occupy the role of study participant due to potential conflicts of commitment. Although the switching of role from study participant to patient partner on the same study after their active study participation is complete may be appropriate, it is not clear what steps are needed to be taken to reduce power dynamics that may form during trial participation and encourage shared decision making (5). For example, can researchers access data collected from a study to identify potential patient partners if prior consent wasn't provided to be contacted about further study opportunities?

Our research also sheds light on the reasons why different approaches to patient partner recruitment may be selected and builds on the work of Vat et al. (11) by expanding their conceptual framework to add on additional subthemes, such as expanding on researchers' characteristics and external/environmental factors, that impact the recruitment of patient partners from researchers' perspectives. While external contextual factors, such as timelines or the

availability of certain approaches, sometimes constrained patient partner recruitment options, other internal factors such as area of research, personal comfort with interviewing patients, as well as patient characteristics and potential ethical issues (such as existing physician-patient power dynamics) also influence the choice of recruitment approach. This finding is consistent with previous studies which found that patient partner characteristics, including lived experience and availability, but also the type of research, and researcher's circumstances all influenced patient partner roles on research projects (28,29). Our study also found this through the influence researcher characteristics, like area of expertise, had on the patient partner characteristics that researchers looked for in potential patient partners. For example, methods researchers often put little weight into the type of lived experience patient partners brought, and more weight into additional experiences such as work experiences and/or research experience. Our results also reflect many of the factors to consider during patient partnerships that were proposed by Parker et al. (30) which included engagement experience, the ability to represent the interest-holder group – something specifically highlighted as a factor relevant to recruiting through partner organisations – as well as specific skills and diversity of perspectives they provide. Interviewees also brought up potential conflicts-of-interest in terms of sharing proprietary information related to pre-grant research, an issue that has been identified in previous studies (5,30). Additional guidance is needed in terms of how to reduce privacy concerns to encourage more equitable recruitment practices.

Overall, this study provided insight into various considerations that researchers consider when looking for patient partners to engage with. A strength of this study was that it included patient partners throughout the study from conception to dissemination. Additionally, this study was

guided by an existing framework and aimed to provide more nuance to the topic as well as diverse representation of researchers from varying career stages and experience in patient engagement (11). Limitations of this study are that it was conducted using a small group of researchers at a hospital-affiliated research institute in an urban setting and thus may not be generalizable to all settings due to availability of certain approaches. Future research may seek to explore how different organizations and settings influence the recruitment of patient partners in research. Additionally, individuals involved in the interview process knew some of the interviewees which may create potential bias in the interviewing process in terms of what is shared. Coding did include a third individual not involved in the interview process and was blinded to the interviews to minimize potential biases. There was also a diverse representation of researchers who had and had not accessed institutional supports at the OHRI to capture varying experiences and approaches.

Conclusion

This study identified strategies of recruiting patient partners not previously described in the literature. It has also highlighted important factors in the recruitment and selection of patient partners from the perspectives of researchers. The results of this study can help inform research teams of methods they can employ to find potential patient partners as well as factors they may wish to consider when choosing an approach. Further research may seek to investigate how to practically and ethically implement the various recruitment approaches. For example, reducing the influence of power dynamics and risk of coercion from clinician-scientists recruiting their patients to be patient partners. Additionally, this study only examined the experiences of researchers in terms of finding patient partners. Future research may wish to explore patient

partners' perspective in the changing engagement space as well as the selection process based on the role patient partners have or will have on research projects.

DECLARATIONS

Clinical Trial Registration

Not applicable

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Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of the Ottawa Health Science Network Research Ethics Board/ Conseil d'éthique de la recherche du Réseau des sciences de la santé d'Ottawa 20230321-01H.

Consent for publication

Implied and written consent was obtained from all individual participants who were interviewed.

Availability of data and materials

The participants of this study did not give written consent for their interview data to be shared publicly, so due to the sensitive nature of the research, supporting data is not available.

Competing interests and conflicts of interest

The authors declare that they have no competing interests or conflicts of interest.

Authors' contributions

Aleisha Fernandes: Investigation; writing—original draft; Writing—review and editing.

Grace Fox: Conceptualisation and methodology; investigation; writing—review and editing.

Ulyana Osorio: Conceptualisation and methodology; Investigation; Writing—review and editing

Holly N. Ellingwood: Conceptualisation and methodology; Investigation; Writing—review and editing

Jacinthe Bisson: Conceptualisation and methodology; Investigation; Writing—review and editing

Debra Turnbull: Conceptualisation and methodology; Investigation; Writing—review and editing

Patricia Pottie: Conceptualisation and methodology; Investigation; Writing—review and editing

Stuart G. Nicholls: Conceptualisation and methodology; investigation; writing—review and editing acquisition; Investigation; writing—original draft; Writing—review and editing.

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