

Albertans for Health Research Network: Form, Fit, and Function

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Abstract

The patient engagement (PE) platform staff of Alberta Strategy for Patient Oriented Research Support for People and Patient Oriented Research Trials Unit developed a patient-powered PE network called Albertans for Health Research Network (AB4HR); an enhanced tool to better connect patient partners and researchers online. AB4HR was developed in response to an identified need—a user-friendly online forum for both patient partners and researchers to access, so that they can better work together, as partners, in health research. We codesigned AB4HR and identified ways to improve the form, fit, and function of an existing registry through discussion groups with patient partners and researchers. We found 3 main themes derived from the perspective shared by patient partners and researchers. Patient partners and researchers agreed that the existing registry provides a forum to connect with one another in an easy, low-barrier way. However, there were opportunities for improvement with AB4HR, including possibilities for greater interaction between patient partners and researchers to promote more collaborative partnerships.

Keywords

patient registry, patient engagement, patient engagement network, Albertans for health research, discussion groups

Introduction

In Canada and around the world, patient engagement (PE) is an integral component of health research that contributes to both improved patient and health system outcomes. Patient engagement is an active process that fosters meaningful collaboration between patient partners and researchers through the entire research cycle (1,2). Researchers and patient partners collectively determine patient-oriented outcomes and design knowledge translation strategies that best target multistakeholder needs (3–5). In Alberta, PE Platform staff of the Alberta Strategy for Patient Oriented Research (SPOR) Support for People and Patient Oriented Research Trials Unit (AbSPORU), patient partners, and researchers codesigned a patient-powered PE network—Albertans for Health Research Network (AB4HR). In this article, we describe our consultation process with patient partners and researchers to identify ways to improve form, fit, and function of the existing registry, as we developed AB4HR. We define patient's partners as those (whether patient, family member/caregiver) with lived experience of health issue(s) and/or with experience of the health care system,

who actively engage in governance, priority setting, or research activities (1). We present our findings within the context of how AB4HR can improve access to engagement and training opportunities, so as to advance health research in Alberta. We anticipate that implementation of AB4HR will support and advance the science of PE based on SPOR's PE guiding principles of inclusiveness, support, mutual respect, and cobuilding (1) to facilitate, in part, the “how” of PE in health research.

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Description

We invited patient partners and researchers who are members of the existing registry. We held discussion groups with (1) patients who saw engagement opportunities posted and as a result partnered with a research team or planned to; (2) researchers who advertised to recruit patients to partner with or who planned to; and (3) patients, family members, caregivers, or researchers who participated in advertised training opportunities. Discussion groups emphasize multiway communication, collaboration, and colearning with an emphasis to inform research or decision-making within projects (6). Whereas in focus groups, data are collected about participant experiences and reported as part of findings from research studies (6–8). We found that conducting discussion groups met our purpose—to elucidate perspectives around how best to enhance AB4HR functionalities (6,8).

We invited patient partners and researchers through an announcement via the existing registry (membership of 170 Albertans). Those attending in-person were offered reimbursement of travel costs. A *Discussion Group Guide* (see Figure 1) was developed by PE Platform staff and external contractors (Habit—a marketing and web-based design team of AB4HR) to determine (1) patient partner and researcher views on preferred features and challenges with the existing registry and (2) enhancement opportunities for AB4HR. Five discussion groups were held with teleconference/videoconference capabilities so that patient partners located in remote/rural areas could participate. The discussion groups were conducted in English, audiotaped, and transcribed using Microsoft OneNote. Fourteen people were engaged in discussion groups (patient partners, $n = 9$; researchers, $n = 5$). Individuals lived/worked in urban and rural areas in Alberta.

We reviewed the responses with patient partners and researchers to ensure that we had accurately captured everyone's thoughts, ideas, and experiences. Next, we grouped responses under “patient partner perspectives” or “researcher perspectives” to understand if there were unique patient partner versus researcher needs when accessing AB4HR. Then, we looked for commonalities in patient partners' and researchers' perspectives. We wanted to ensure that AB4HR would address multiple needs, streamline common functionality, and promote a user-friendly interface. As a result of undertaking this process, we identified 3 themes from our findings (see Findings section). Finally, we sent a consolidated summary of our findings to all patient partners and researchers who took part in the discussion groups to determine whether responses were accurately categorized or if there were missing data. No further input was provided.

Findings

Three main themes (see Table 1) that arose were:

1. The existing registry is an effective way to keep informed about PE opportunities in health research,

Questions for patient partners^a

1. What are some of the features you like about the existing registry?
 2. What are some of the features you do not like about the existing registry?
 3. We have two new features we're hoping to include with AB4HR:
 - a) *One of the new features we are considering for AB4HR is a message board for each unique opportunity. What are your thoughts about being able to communicate with researchers directly in AB4HR?*
 - b) *We would like to create a drop-down field with additional options to select from, including your age range, how you heard about AB4HR, and what ethnicity you identify with. We can use this information to help ensure that we have a diversity of Patient Partners signed up to AB4HR. What are your thoughts about filling out these fields of information?*
 - c) *Do you have any other suggestions about the types of features you would like to see in AB4HR?*
 4. *There is a provincial initiative (Connect Care) underway by Alberta Health Services and other partners to bridge information exchange between patients, providers, and the health system. One feature that is being explored, is the option for patients to gain access to AB4HR when logged on to Connect Care. What are your thoughts about the option in Connect Care to access health research opportunities to become involved as Patient Partners?*
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Questions for researchers^a

1. What are some of the features you like about the existing registry?
 2. What are some of the features you do not like about the existing registry?
 3. What are your thoughts about how we post opportunities on the existing registry?
 4. We have two new features we're hoping to include with AB4HR:
 - a) *One of the new features we are considering for AB4HR is a message board for each unique opportunity. What are your thoughts about being able to communicate with patients directly in AB4HR?*
 - b) *We would like to create a drop-down field with additional options to select from, including patients' age range, how they heard about AB4HR, and what ethnicity they identify with. We can use this information to help ensure that we have a diversity of patient partners signed up to AB4HR. What are your thoughts about patients filling out these fields of information?*
 - c) *Do you have any other suggestions about the types of features you would like to see in AB4HR?*
 5. *There is a provincial initiative (Connect Care) underway by Alberta Health Services and other partners to bridge information exchange between patients, providers, and the health system. One feature that is being explored, is the option for patients to gain access to AB4HR when logged on to Connect Care. What are your thoughts about patients having the option in Connect Care to access health research opportunities to become involved as Patient Partners?*
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^aA brief overview of the context of the project was provided to patients and researchers before commencing the discussion groups

Figure 1. Discussion group guide. AB4HR indicates Albertans for Health Research Network.

Table 1. Themes From Discussion Groups and Patient and Researcher Observations.

| Themes | Patient and researcher observations |
|---|--|
| (1) The existing registry is an effective way to keep informed about PE opportunities in health research, and users appreciate the personalized emails from the PE Platform staff | <ul style="list-style-type: none"> • Easy-to-read • Easy to navigate • Helpful to have all info in one place • Easy to be kept up-to-date • Emails from PE Platform staff • Email sent out to members provides additional awareness • First screen keeps you up-to-date • PE Platform is a “broker” between patient partners and researchers |
| (2) The proposed look and feel for AB4HR are well received (ie, improved interactivity, enhanced opportunities for patient–researcher matching and integration into other patient systems). | <p>Message board</p> <ul style="list-style-type: none"> • Having an online interactive system and online opportunities would increase engagement from individuals in remote areas • More frequent contact with research team members encourages engagement • Patient partners become more comfortable and empowered • Relationship begins forming during this interactive stage among all partners • Creation of groups or communities of practice so similar projects can be discussed <p>Drop-down user profile information</p> <ul style="list-style-type: none"> • More information around demographics is important for better matching for opportunities that are posted • Justify that demographic information is required for reporting purposes and that most standard forms ask for this type of information so public is likely used to this practice • Privacy concern around detailed health info being stored in the registry database <p>Integration with other system</p> <ul style="list-style-type: none"> • Makes sense to integrate other systems to get more people engaged • Opt-in is preferred than having to opt-out of the registry • Consider broader service platforms other than siloed health system platforms with multiple barriers |
| (3) The creation of user roles specific to researchers and patient partners in AB4HR is an important and valuable upgrade | <ul style="list-style-type: none"> • Customize level of detail required for researcher versus patient partner user profiles • People may have multiple perspectives they may choose to sign up as a researcher and patient partner (more than one type of profile) • Level of information should be different for each profile and the profiles should not be linked (privacy) |

Abbreviations: AB4HR, Albertans for Health Research Network; PE, patient engagement.

and users appreciate personalized emails from PE Platform staff. Via the existing registry, patient partners are recruited to engage in projects relevant to their lived experiences and have roles on committees/councils to advise on projects. They provide perspectives on research design and tools (such as surveys) and codevelop presentations about study results. Suggestion for AB4HR was to maintain “personalization,” whereby PE Platform staff act as a conduit to facilitate interactions between patient partners and researchers. AB4HR must be user-friendly to facilitate comfortable and personalized experiences among PE Platform staff, patient partners, and researchers.

2. The proposed look and feel for AB4HR are well received: Patient partners and researchers like the proposed discussion boards and instant messaging features of AB4HR to improve interactivity. To better match patient partners and researchers with engagement opportunities, needs/interests, and demographic characteristics that are collected and shared will be helpful. A future suggestion was to

integrate AB4HR with patient-oriented clinical information systems (CIS) to improve visibility and reach of health research opportunities with wider audiences. Clinical information systems were defined as infrastructure to improve access to information between health care teams and patients. Patient partners raised the need to safeguard their information on each unique project, so that it can only be accessed by the respective research teams.

3. The creation of user roles specific to researchers and patient partners in AB4HR are an important and valuable upgrade: Capturing lived experience of users is important so that we can understand the perspectives users bring. Customization of both amount and type of information provided in patient and researcher profiles helps to better match individuals and groups based on experiential knowledge. Capturing “dual” roles of users (ie, as a patient partner and researcher—having 2 profiles) in AB4HR was identified as a need, so that researchers could partake in engagement opportunities, and patient partners could advertise engagement opportunities.

Lessons Learned

We have identified several lessons learned and applied the findings from discussion groups to guide and inform the plan and design of AB4HR. To our knowledge, this is the first time that discussion versus focus groups were used to consult with patient partners and researchers on the topic of patient registries. We found that discussion groups encouraged more open and flexible discussion about AB4HR. The fluidity of moving beyond strict guides or protocols allows the conversation to evolve more naturally, which was important to encourage contribution and inclusivity from our patient partners and researchers. It takes time and coordinated efforts to plan for discussion groups and requires resources to carry it out to completion.

Our findings are concurrent to evidence about how best to develop patient-powered networks, like AB4HR. For example, authors' findings from a few studies validate the value of registries in promoting meaningful partnerships between patient partners and researchers (7,9–13), an outcome which is attributed to patients and researchers sharing responsibility in designing, governing, and evaluating services and research (10,13,14). Registries are a mechanism to better capture heterogeneity of patient-reported outcomes using one interface (15) and to promote the relevance of patients' lived experience in research (13). Elements of success for patient-powered registries include a clear purpose, well-designed technology and recognition of multiple lived experiences and roles of both patients and researchers (9,14). Concerns about responsible use of data, patient privacy, and appropriate management and sustainability of the registry were also factors that might influence engagement (7,9).

Our findings also present future opportunities to consider. AB4HR is a valuable system with the primary purpose to promote PE opportunities in health research. While these type of specific registries offer ample benefits (ie, priority is PE, control and access to data, improved access to patient partners and researchers) (14), it is suggested that to maximize the utility of patient-powered information systems, there needs to be better regional harmonization. The desired state is to have seamless transition between multiple registries (16,17). Potential for integration of AB4HR with other patient registries and CIS is a medium-term objective (over the next 5 years) and alignment with future provincial, and possibly national-level, efforts are long-term objectives.

Knowing our patient partners and researchers contributed to codesigning AB4HR increases the legitimacy of the network that is aimed to bring patient partners and researchers together to form a community of practice. Patient partners and researchers want a user-friendly and personalized network, and one that is efficient in facilitating involvement in engagement opportunities. Patient partners and researchers want to be a part of this initiative because they see the value and return on investment of their time. They can envision using AB4HR and find it more accessible to learn about engagement and training opportunities.

Conclusion

We anticipate that AB4HR will contribute to the science and practice of PE in health research. We will integrate AB4HR as part of our services offered by AbSPORU to support patient-oriented research. We will evaluate the effectiveness of this network and examine the impact on patient and health system outcomes. Through this initiative, we developed AB4HR to better promote meaningful PE opportunities, so that we can collectively improve research outcomes in Alberta (1).

Authors' Note

JR, EM, KK, and IN made substantial contributions to the conception, design, acquisition of data, analysis, and interpretation of data. JR, EM, KK, IN, IA, EM, LL, and SA were involved in drafting the manuscript and revising it critically for intellectual content. Ingrid Nielsens is also affiliated with Cumming School of Medicine, University of Calgary, Alberta, Canada. Israel Amirav is now affiliated with Patient Engagement Platform, Alberta SPOR SUPPORT Unit, Alberta, Canada and also with Dana-Dwek Childrens' Hospital, Tel Aviv Medical Center, Israel. Emily CM Macphail is now affiliated with Cumming School of Medicine, University of Calgary, Alberta, Canada. Lise-Anne Lavigne and Sheila Asis are now affiliated with Patient Engagement Platform, Alberta SPOR SUPPORT Unit, Alberta, Canada.

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

We completed the self-guided screening for Research Ethics Board review through Alberta Innovates' ARECCI Ethics Guideline and Screening Tool and given the nature of the study, such that we consulted with patient partners and researchers as subject matter expert, the intent and objectives of the data collection did not require a full ethics application submission and was considered a quality improvement project. Before beginning each session, patient partners and researchers agreed to have the data collected and shared in an aggregate format with the developer and for academic publication purposes so that others could learn from our experiences.

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