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Building patient-oriented research capacity by co-designing a research handbook for patient partners

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1. Background

Patient engagement is central to conducting research that yields relevant evidence to the needs of patients and their families [1]. The positive benefits include increasing the acceptability of the research design, identifying and mitigating barriers to participation, minimising bias, and increasing relevance of the research findings [1,2]. To support this type of participation, information resources are needed. Although there is an agreement that information resources are necessary for full participation [3,4], examples of resources are limited [1,5]. At the onset of the COVID-19 pandemic, our team co-designed a research handbook to inform patient partners about the research process, roles and responsibilities of all team members, ethical principles of research, and other useful information.

In this article, we describe how developing a research handbook for patient partners not only resulted in a valuable information resource, but also allowed us to evaluate and strengthen partnerships while building patient-oriented research capacity. Developing a similar handbook could be an effective strategy for research groups to build, evaluate, and affirm community partnerships that may have been challenged during the COVID-19 pandemic.

2. Approach

The research team used a co-design approach to create the research handbook to ensure a useful final product for the population it aims to serve [6–8]. Co-design entails all stakeholders jointly working together to explore ideas and find solutions to challenges that arise [8]. We built on past co-design experiences to iteratively develop the Handbook [9].

First, we determined key information to be included and divided the content into three sections: 1) background and information on the research process; 2) research areas, and 3) the roles and responsibilities of all team members. The Handbook then underwent iterative review and revision to improve flow and ensure accurate messaging and accessibility of language. Two key documents informed the development; first, the Community Scholar Program guidelines [10]; and second, a discussion paper on person-centred care developed by a patient partner within the eConsultBASE™ team.

3. Discussion

3.1. The importance of co-design

A co-design approach made it possible to identify the most pertinent information to include in the Handbook. Patient partners played an integral role in flagging specific sections that should either be further elaborated or omitted. For example, patient partners expressed the importance of a privacy and confidentiality statement that expands upon traditional understandings of privacy and confidentiality within research to respect the confidentiality of patient partners' personal stories, which may be shared in meetings (Fig. 1).

3.2. Equitable partnership through communication

To build capacity for patient engagement, relationships between researchers and patient partners need to be fostered over time [11] and should rely on open and supportive communication and a commitment to learning from each other [3]. The Handbook served as an opportunity for researchers and patient partners to evaluate and strengthen their partnership. For example, the Handbook outline was based on the Community Scholar Program, which describes the role of patient partners. The development team felt that for the relationship to be equitable, the role of the researchers in patient engagement should also be clearly defined. The roles and responsibilities were created through an open conversation regarding individuals' expectations of themselves and their team members, resulting in clear roles and responsibilities for all team members (Fig. 2).

Additionally, a more equitable relationship was built by using language that reflected person-centred care values and principles. For example, when discussing the term "patient partner", the group agreed the term itself was not as important as its definition. The team chose to continue using the term because it is commonly used and defined it as "people that bring lived experiences to the research process to help focus the research on what is important for the community to improve the

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Fig. 1. A section of the *Research Guide for Patient Partners* addressing the confidentiality of patient partners' information and personal stories.

Fig. 2. A section of the *Research Guide for Patient Partners* highlighting the roles and commitments of the research team.

healthcare system and the experiences of people within it."

The partnership was informally evaluated iteratively through consensus-building during the development process. When the Handbook was completed, everyone responded to short open-ended questions to share their thoughts regarding their experience. The responses resulted in the outline for this manuscript. More methodologically rigorous evaluation may take place during future projects.

3.3. Building capacity for patient-oriented research

Developing the Handbook was an excellent way to build and foster existing researcher-patient partner relationships, while creating capacity for patient engagement amongst those newer to research. The exposure to this work is particularly valuable for individuals entering research careers, as it grounds all research team members in person-centred principles and values. Future modifications will be made based on the feedback and information needs of future patient partners joining the team.

4. Conclusion

A research handbook for patient partners is a useful tool for patient partners, and it helps to create a meaningful and informed partnership between patient partners and researchers. Developing the Handbook became an effective way to establish and reaffirm this partnership while facilitating important conversations about patient engagement. We encourage other researchers to consider creating information resources to support patient partners and build capacity for patient-oriented research.

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Patient Identifiers

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Declaration of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2022.07.001.

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Tess McCutcheon[a], James LaPlante[a], Christine Bibeau[b], Lynn Cooper[a], Jessika Hammond[a], Mary Helmer-Smith[a], Deanne Houghton[a], Katharina Kovacs Burns[c], Donald Mastin[a], Kevin Turner[b], Clare Liddy[a,d,e,*]

[a] *C.T. Lamont Primary Health Care Research Centre, Bruyère Research Institute, Ottawa, Ontario, Canada*

[b] *eConsult BASE™ Manitoba, Manitoba, Canada*

[c] *School of Public Health, Edmonton Clinic Health Academy, University of Alberta, Edmonton, Canada*

[d] *Department of Family Medicine, Faculty of Medicine, University of Ottawa, Ottawa, Canada*

[e] *Ontario eConsult Centre of Excellence, The Ottawa Hospital, Ottawa, Canada*

[*] Corresponding author at: Department of Family Medicine, University of Ottawa, 600 Peter Morand Crescent, Room 201, Ottawa, ON, K1G 5Z3

E-mail address: cliddy@uottawa.ca (C. Liddy).