Evaluation of Experiences and Impact of Patient Engagement on e-Health Research: A Qualitative Study

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Abstract

Background: Health technology has increasingly moved toward adopting a "user-centred design" approach to include the user/patient throughout the innovation and design process; however, few studies have evaluated the patient's experience of such an engagement.

Objective: The aim of this study was to explore the role of patient engagement (PE) within e-health innovation research.

Method: Using qualitative descriptive methodology, semi-structured interviews were conducted with eight participants (patient partners and research/development team members).

Findings: Key themes were centred on enablers of, challenges to and methods of improving PE.

Conclusion: PE must be prioritized from study conception, explicitly programmed into study conduct and valued by integrating patient partner input.

Key Points

- This study provided a multi-stakeholder perspective on patient engagement (PE), revealing that stakeholders' perspectives differed and must be considered separately when planning for engagement.
- This study identified strategies to improve PE during the development of an e-health tool, including providing support for patients throughout the process, ensuring thorough team communication, making patients feel valued for their contributions and fostering a positive research environment.
- Overall, PE helped ensure the relevance, usability and appropriateness of an e-health tool for different patient demographics; however, the process of PE should pay special attention to recruiting representative patient populations.

Introduction

Patient engagement (PE) is a meaningful and active collaboration in governance, disease diagnosis and management, priority setting, conducting research and knowledge translation (CIHR 2014). With the shift away from paternalism in healthcare, PE in health research has increasingly become a key research priority in Canada (Manafo et al. 2018). E-health is a category within digital health that denotes the wide range of information, expertise and communication technologies that support health-related fields, including health surveillance, education and healthcare delivery (Baker et al. 2014). Despite its many potential benefits to patients, existing e-health services are largely technology-driven rather than being personalized and user-centred, resulting in tools that fail to address individualized patient goals and that, thus, cannot be widely adopted (Cowie et al. 2013). In response, *MyDiabetesPlan* (*MDP*), a web-based shared decision making and priority-setting patient decision aid, was developed by engaging patients in the research process of e-health tool development in order to create a more user-centred e-health toolkit (Yu et al. 2014).

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P = Patient, caregiver and knowledge user.

There is a lack of investigation into PE within e-health, which, in today's digital climate, is a deficiency (Leung et al. 2019). Furthermore, few studies have explored patients' perspectives of and experiences in such an engagement. Existing studies tend to leave research topics unspecified and predominantly report only on academic researchers' experiences (Bhati et al. 2020). Moreover, PE within research has only recently garnered attention in North America and warrants findings specific to local populations (Bhati et al. 2020). With the role of patient partners (PPs) in improving research feasibility, acceptability, rigor and relevance, this Engage Multi-stakeholders for Patient Oriented-research Wider Effects and Reach (EMPOWER) Award project explored the experiences and perspectives of the PPs and researchers from the initial research project to guide PE in the future (Forsythe et al. 2019).

The purpose of this study was to explore the role of PE within Canadian e-health innovation research using our experience with *MDP* as a case study. We aimed to identify how patients were engaged, the impact and benefits of this engagement, challenges that were faced and how PE can be more effective moving forward. The PE in research framework was used to guide this line of inquiry (Hamilton et al. 2018). By involving both PPs and research team members, we obtained a multi-stakeholder perspective.

Method

Our previous work developed and trialled *MDP* in a multi-centred randomized controlled trial (Yu et al. 2020). Recently, through the EMPOWER grant, we explored patients' and clinicians' experiences regarding its integration into clinical care and interprofessional stakeholder involvement to assess the implementation potential of *MDP*. Thus, our study acts as an extension of the broader *MDP* project (Sivakumar et al. 2021). PPs were consulted frequently as members of the research team throughout all phases of the research program, from innovation ideation, development and testing to implementation. In the development of this evaluation of PE study, one of the authors (PW) was consulted to arrive at the most relevant research question from a PP's perspective.

We used qualitative descriptive methodology as it offers an in-depth understanding of participants' experiences and impact of PE. We adhered to the Guidance for Reporting Involvement of Patients and the Public–Long Form (GRIPP2–LF) reporting checklist (Staniszewska et al. 2017).

To date, *MDP* has involved a multi-disciplinary team that consisted of PPs ($n = 3$), software development team members ($n = 2$) and research team members ($n = 13$). In the EMPOWER study, these same members in addition to Ontario Ministry of Health participants were end-user participants. In order to gain the experiences of all those who worked on *MDP*, recruitment occurred by contacting PPs and team members through e-mail and obtaining informed consent.

Data were obtained through semi-structured interviews. The interview guides (one each for PPs and research team members) explored experiences with PE in *MDP*, challenges that were faced and how PE in research can be more effective moving forward, the contents of which were based on the GRIPP2 framework. Interviews were conducted virtually via Zoom due to the COVID-19 pandemic by research team members trained in qualitative interviewing (RP and KZ). All interviews were audiotaped, transcribed verbatim and annotated. Content analysis was carried out in an iterative fashion alongside data collection (Elo and Kyngäs 2008; Korstjens and Moser 2018).

Results

We interviewed eight participants (Table 1).

We describe participants' views on ways to sustain PE and the impacts, enablers and hindrances of PE. See Tables 2 and 3 for representative quotes (available online at www.longwoods.com/content/26775).

TABLE 1.
Participants

Stakeholder group	Participant
PPs	Patient living with type 1 diabetes, has been a PP from October 2015 to present. Patient living with type 2 diabetes, has been a PP from February 2016 to present. Patient living with type 2 diabetes, has been a PP from December 2017 to present.
Research team members	Physician and site lead Physician and site lead Registered nurse Physician Research coordinator/assistant
Development team member	Software developer

PPs' experiences and perspectives

Ways in which meaningful PE was sustained

PPs felt valued and "listened to" through integration into the entirety of the research process. They appreciated providing input for, testing and evaluating the e-health tool and being consulted on the selection of study outcomes and data collection tools. This was enabled by frequent meetings with the research team.

They reported that their sentiment of feeling respected, valued and able to contribute (despite initially thinking that their own non-medical backgrounds would be a limitation) helped sustain PE. They felt empowered to apply their unique skills, coming from different cultural and ethnic backgrounds, thus contributing to a collaborative team environment. They also identified the creation of opportunities that demonstrated the value of PE; for example, PPs were given the opportunity to present at conferences alongside research team members.

Positive and negative results of PE and its impacts on the research and individuals involved

PE provided first-hand patient perspectives and experiences, which helped ensure the tool's relevance to patients and guided the direction of the research. PPs helped refine the tool's user interface and ensured patient understandability of the tool; they also helped contextualize the tool in terms of language barriers, generational gaps and cultural nuances. PPs themselves were able to get the perspective and support of other individuals with diabetes while learning more about the condition. Furthermore, learning about the time and effort that goes into conducting research was paradigm-shifting for the PPs, and they developed a greater appreciation for the process. PPs felt empowered and confident by the act of providing their perspectives and creating impactful change, and experienced fulfillment from long-term involvement with the research project.

Contextual and research process factors that enabled the impact of PE

PPs' prior interest in diabetes-related topics and their motivation to self-educate was a contextual factor that spurred their engagement. In terms of the research process, PPs felt comfortable and confident voicing their concerns in the team environment and were supported if needed. Having differing contributions be valued helped create a positive experience for the PPs and, in particular, a trusting relationship with team members before and throughout engagement further promoted the same.

Contextual and research process factors that hindered the impact of PE

PPs noted that their comprehension and insecurity about what they bring to the table were potential hindrances to full engagement. A contextual challenge was encountered by patients who spoke English as a second language, which at times acted as a language barrier. Similarly, PPs were sometimes challenged and had difficulty understanding everything discussed at meetings, especially medical terminology. Regarding the research process, PPs found it difficult to maintain motivation during periods when there was no communication from the researchers.

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Researchers' perspectives and experiences

Ways in which meaningful PE was sustained

Throughout the research process, researchers appreciated that PPs were engaged consistently alongside research members. Researchers also valued PPs as the main "experts" on diabetes, and their personal experiences and inputs were valued equally to inputs by other research members.

Positive and negative results of PE and its impacts on the research and individuals involved

The first notable impact patients made was providing diverse perspectives and experiences. These insights not only helped to identify discrepancies between researchers' assumptions about patient knowledge and opinions and the reality for patients; these insights also would sometimes change the direction of the research itself. Specifically, in considering the development of an e-health innovation, patients played a critical role in ensuring the relevance, practicality and usability of the tool, as well as other patient-facing research materials, for patients. Researchers particularly appreciated that patient input improved the efficiency of the research. However, researchers noted that a somewhat negative impact of PE included increasing the amount of time needed to conduct research and also that it was important to take this additional time to ensure that the final outcome was appropriate and justified.

Contextual and research process factors that enabled the impact of PE

Firstly, institutional support and resource allocation to PE was a facilitator to *MDP* as there was a large amount of support, but researchers noted that it was a challenge within the research community, overall. Additionally, researchers noted that relationship building between the research team and the PPs both before and during the project was critical to fostering engagement and successful partnership. Similarly, the effort that researchers took to speak the same "language" as patients was identified as an enabler of PE.

Contextual and research process factors that hindered the impact of PE engagement

Researchers expressed several challenges to PE. Ensuring that PPs constantly feel valued and engaged was identified as a challenge; however, within the context of *MDP*, researchers felt that PPs were enthusiastic and dedicated. More broadly, researchers held concerns regarding the process of PE, which included the inherent power differential between PPs and research team members and how our sample of PPs may not be representative of the whole patient population of interest.

Discussion

Prior studies have shown that the usability, understandability and relevance that PPs bring to e-health tools lead to increased uptake of new technologies (Lupton 2013).

Our PPs reported a predominantly positive experience with PE, which was attributed to feeling valued by the research team, finding a community of other diabetes patients, learning about diabetes and feeling empowered about disease management. Many of these positive findings are consistent with a study by Forsythe et al. (2019), which analyzed PE across 126 studies that described the contribution(s) of engagement to their project; however, our study is one of the few that investigated challenges and enablers expressed by PPs themselves specifically within the context of e-health. Age, language, cultural background and prior knowledge impacted the ease with which patients could engage with the research and the tool being developed. The PPs' motivation to self-educate and the research team's supportiveness facilitated their engagement; however, an area of improvement was the need for increasing the regularity of communication with patients.

Researchers found it valuable when patients provided first-hand experience and input as it validated their work and grounded it in real patient perspectives. Their feedback on experiencing the disease, financial constraints and lack of knowledge, education and accessibility to family physicians was insightful. Researchers found that *MDP* engaged patients meaningfully, with patients being extensively involved throughout the research process. Within the literature, one of the concerns that researchers have for PE is its potential tokenistic usage of patients (Carroll et al. 2017); our findings demonstrate that treating patients as an equal member of the team and a previous positive relationship with a core research member may mitigate this concern. Other facilitators to engagement included increased institutional support and using accessible language. Researchers emphasized the challenge of PPs not being representative of the whole population of interest, which is consistent with the literature (Carroll et al. 2017). Although our PPs had different cultural backgrounds, there should be more measures to involve a wide range of patient populations and uphold equity, diversity and inclusion. A centralized process for patient recruitment and engagement may help address this; however, the difficulty lies in doing so in a meaningful and ethical way (Bishop et al. 2018).

Limitations included our limited sample size, which may not be representative of the diabetes patient population or other e-health research teams.

Conclusion

The value-add of PE was its role in creating an e-health tool that is indeed beneficial and sensitive to end-users' needs. Our work suggests the need for more centralized processes for PE that also involves more diverse patient populations while ensuring adequate relationship building between the research teams and partners; strategies to improve PE during the development of an e-health tool include providing support for patients throughout the process, ensuring thorough team communication, making patients feel valued for their contributions and fostering a positive research environment. HQ

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