Perspectives in Practice

Lived Experience as a Distinct Information Source: A Case Study to Improve E-Health Products for Adults With Type 1 or 2 Diabetes Starting Insulin

Jennica Nichols MPH *; Stephanie Boutette MPH, RD; Krista Banasiak MA

Diabetes Canada, Toronto, Ontario, Canada

Key Messages

- Patients are a distinct stakeholder group.
- Lived experience is a distinct knowledge source, and we should be prioritizing patients' engagement in the design of new e-health resources.
- Including patients' perspectives in the design of e-health tools results in a superior product.

Introduction

The Internet is an important source of health information. Results from the United States' Health Information National Trends Survey 4 found that 77% of people (N=2,222) who had used the Internet in the past year had done so to find health-related information, and 46% reported the Internet to be their first source for this information (1). It is important to recognize different rates and patterns of online health-information-seeking behaviour based on demographic and/or socioeconomic factors (2,3), so this overall trend creates an impetus for studying and understanding how to develop effective e-health interventions.

Moreover, the Internet's interactive capacity allows for the implementation of novel participatory programs and interventions aimed at improving individual health outcomes (2,4). E-health interventions have the potential to empower patients by providing new opportunities to make evidence-based choices that extend beyond usual geographic limits in order to improve patients' knowledge (2,4). Research suggests that e-health technology positively impacts healthcare for patients with chronic diseases: it improves patient-provider communication, contributes to behaviour changes, aids in

metabolic control and improves treatment adherence (5–8). However, despite their potential, products that fail to pay adequate attention to users' perspectives during the design stage were poorly used (9,10). Based on our case study, we assert patient-centred design can result in higher quality e-health products that are more readily taken up by users (10,11).

Patient-centred design

Patient-centred design provides opportunities to appeal to patients at any stage of their disease's development: determining the project's focus, developing initial content, refining the product and improving usability (9). Although they are a historically neglected stakeholder group, patients have perspectives, experiences and preferences in all elements of research; acknowledging them ensures that patients' concerns are prioritized. Patients and healthcare providers (HCPs) prioritize different elements of diabetes self-management and can have misaligned understandings about barriers to successful management (11–13). For example, a review found that the most common reason for intentional nonadherence to medications was an effort to avoid side effects (11). Despite this, there was no evidence that physicians recognized side-effect avoidance as a reason for intentional nonadherence (11). Patients and HCPs, therefore, represent different knowledge sources for the development of evidence-based and effective e-health products for patients.

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* Address for correspondence: Jennica Nichols, MPH, University of British Columbia, Room 226, Klinck Building, 6356 Agricultural Road, Vancouver, British Columbia V6T 1Z2, Canada.
E-mail address: jennica.nichols@alumni.ubc.ca

Part of developing effective e-health interventions for patients includes understanding when and how to include patients most effectively. In addition to the common challenges associated with engaging patients, such as the need for additional resources (e.g. time, funding), variable health literacy and patients' barriers (e.g. lack of time or means of transportation) (14), e-health faces an additional challenge: it lacks a working framework to facilitate patients' engagement.

In this article, we present a successful case study of engaging people living with diabetes (PwD) in the design of a video series that supports insulin start-ups. Despite grappling with the aforementioned challenges, using a patient-centred design approach in the development of our e-health tool enhanced the video in ways that would not have been possible if it had been designed by researchers and HCPs alone. We briefly describe the project, highlight the strengths of our approach and present lessons learned, with particular focus on the value added as the result of patient involvement. Our goal is to encourage others to build upon this research by employing patient-centred design in their work in e-health tool development for patients.

Methods

Our project aimed to create a series of online videos to support PwD who are thinking about starting insulin and those who are new insulin users. Our work was informed by a philosophy of empowerment, privileging individuals' sense of control of and responsibility for their own quality of life (15,16). Empowerment philosophy is patient centred, which is particularly relevant to diabetes care because day-to-day management of the disease lies in the hands of patients. Research demonstrates that interventions that prioritize empowerment have been effective in changing individuals' self-management behaviours and improving health outcomes (17–19).

The original script was created by a team of HCPs, 2 professional script writers and Diabetes Canada[1] staff members. It included information about the psychosocial aspects of starting insulin, the parts of an insulin pen, an instructional demonstration of injecting insulin and answers to frequently asked questions. To engage PwD and gather feedback on the script content prior to production, we created a low-budget video prototype in which volunteers read the script.

Participants were recruited through online and paper advertisements, as well as in-person recruitment from a Toronto-based diabetes clinic. Cognizant of the importance of language use, communication style and cultural context to end-user learning outcomes, we purposively selected participants for our focus groups who varied in age, socioeconomic status and ethnic background. In total, 4 2-hour focus groups were held: 1 virtual focus group with HCPs across Canada (n=13) and 3 in person with PwD (n=9), all of whom had experience in injecting insulin. To solicit the targeted participants' input, the videos were played in segments, with each segment followed by a semistructured group discussion. The focus groups' inputs were transcribed and coded for themes relating to language use, message tone and audience comprehension. The script was then edited accordingly by Diabetes Canada staff and HCPs to reflect PwD's insights.

Results

Diabetes Canada staff and HCPs considered that the original script provided helpful instruction founded on evidence-based practices

[1]The Canadian Diabetes Association underwent a name change in February 2017 to become Diabetes Canada; at the time of this work, the organization was called the Canadian Diabetes Association.

and clinical experience, all conveyed in a positive and warm tone. However, hearing PwDs' lived experiences in starting insulin led us to evaluate the script differently. PwD's involvement highlighted the need to address issues of language, tone, missing content and use of visuals. Engaging PwD led to many script changes that speak to the lives and actual experiences of those living with diabetes that otherwise would have been missed (see the Supplementary Appendix for video examples).

Script improvements

The involvement of PwD helped to highlight the discrepancies between clinical and everyday language and helped to ensure that the tool to be created would be easily understood by a broad audience. The original script used phrases HCPs commonly use in practice, yet participants found the content confusing and identified phrases that needed simplifying. For example, although "prime your pen" is a well-known phrase for HCPs, our participants felt a full explanation was required and advised that adding "getting rid of the air in the needle and making sure that the pen is working" would be more readily understood.

The emphasis on everyday language also helped decision making in circumstances where the team was in disagreement. For instance, HCPs debated whether blood glucose, blood sugar or both should be used throughout the script. Focus group participants never once used blood glucose in their discussions, suggesting that this term is reserved mostly for clinical settings. Participants actively emphasized that blood sugar should be used consistently and exclusively so as to improve both comprehension and relatability.

Tone

Participants' interpretations of the videos led the team to conclude that the intended warm tone was not received. Participants felt the video's narrative was too negative, that it emphasized what not to do as opposed to what to do, and that the educator's dialogue was direct and cold. Specific suggestions by the group included "reiterate that insulin is just another tool to help manage your blood sugars," "emphasize that diabetes is not 'the end,'" and "keep the steps simple and calm." Their feedback helped to reframe the content so that it was more positive and explicitly delivered the material in an open, friendly and nonstigmatizing manner. We believe this improved our efforts to engender feelings of confidence and self-efficacy in audience members.

Content

Participants' feedback helped to identify missing content. Participants reflected on questions they, themselves, had had and information they had lacked when starting insulin. Although we had felt that our script sufficiently addressed issues pertinent to insulin start-ups, PwD's own experiences shed light on common concerns and problems we would not otherwise have considered. For example, participants described concern when they found differences between the dosages of insulin they took compared to the dosages of others. This caused a sense of uncertainty and distress and contributed to feelings of self-doubt. To address this, we added a section of frequently asked questions to help allay the concern. Incorporating PwD's insights helped to align the end product more closely with PwD's real-world experiences and to increase the video series' effectiveness.

Use of visuals

Participants reinforced the need for high-quality visuals in this instructional video so as to clarify areas of confusion and enhance its relevance and effectiveness for end users. Animations, text bubbles and step-by-step visual demonstrations were added to augment the material provided verbally. Doing so provides more