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Co-design of rehabilitation programming

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Co-design of rehabilitation programming

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Table of contents

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Editorial: Co-design of rehabilitation programming

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Editorial on the Research Topic
Co-design of rehabilitation programming

Co-design is an approach in health research that incorporates meaningful lived experience engagement across any stage of the research or quality improvement process (1). Engaging with individuals with lived experience can be used to accomplish discrete goals, such as development of technologies, educational materials, or programs, or it can serve process or structural outcomes, such as reducing research waste, enhancing service delivery or improving organizational governance (2). This type of person-centered approach is critical in the field of rehabilitation, due to the unique needs of individuals with varying levels and types of disability experience, as well as differing life situations and environmental contexts. However, much of the existing literature focuses on primary services (2, 3). There is variation in how co-design is defined and implemented (1, 2), and as more literature emerges on this topic in rehabilitation care, it is important to understand the breadth of the field as it continues to grow. We created this Research Topic to showcase current practices and implementation of co-design in rehabilitation research and service delivery, and to encourage further reflection on how the field can move forward in a socially responsible and impactful way.

This Research Topic consists of 10 articles, each describing important aspects of co-design approaches and how they can be applied in a rehabilitation setting. Among the articles, a common theme was using co-design as a method of identifying factors that may influence the success of various rehabilitation programs, educational tools, or technologies. Studies included multiple and diverse stakeholder groups in their research, demonstrating the importance of using a comprehensive approach to gather perspectives.

A common theme among the original research and methods papers was the use of co-design in working towards discrete outcomes rather than impacting service delivery or governance. Reitzel et al. used a co-design approach that included caregivers, clinicians, and healthcare managers and discussed innovative solutions to enhance access and engagement in pediatric telerehabilitation. Through these discussions, they found that communication, consistency and connection were key factors that could enhance engagement in pediatric telerehabilitation and reduce barriers to care (Reitzel et al.). Shi et al. used one-on-one interviews with a variety of stakeholders within a community-based SCI organization and a rehabilitation center to identify barriers and facilitators as well as collaboration processes to delivering a peer mentorship program for people with SCI; they identified 10 factors that could influence a program's success. Eggiman-Ketter et al. used a similar approach to identify enablers and barriers to implementing an interdisciplinary experiential learning program for undergraduate and graduate students at a local rehabilitation center, resulting in 15 recommendations for program development. Clanchy et al. used a three-phase approach to prioritize end-user feedback regarding a new rehabilitation device and incorporate it with perspectives from other stakeholders to adapt product development. The authors also provide practical suggestions for other researchers who aim to co-design rehabilitation technologies based on their experiences (Clanchy et al.). Jeyakumaran et al. embedded co-design within the development of a novel assistive device platform and described their successes and lessons learned to inform ongoing and future initiatives. Craven et al. focused on knowledge translation, creating a co-designed podcast as an educational tool to disseminate the findings of a recently developed clinical practice guideline. The methods paper presented by Cimino et al. describes the plan to use co-design to facilitate the development of personalized mobility programming for persons with mobility impairments. Two articles described using co-design to address organizational structures or service delivery as higher-level outcomes. The community case study by Giroux et al. adopted a co-design approach to perform a community-based consensus exercise focused on strategic priorities and future directions for a SCI network in Canada. A brief research report by Seko et al. describes the process to co-design a novel service delivery model to support the transition from pediatric to adult care, highlighting the importance of open communication and iterative program development. Lastly, the perspective article by Bourke et al. shares fundamental principles that are essential to implementing co-design approaches in a meaningful and authentic way. This article leaves readers with the challenge of progressing co-designed research towards co-production, a collaborative approach that centres equitable and ethical practices focused on reflective dialogue (Bourke et al.).

The articles submitted to this topic were focused on the fields of pediatric and spinal cord injury rehabilitation. These populations often require extensive and ongoing rehabilitation care throughout much of their life, emphasizing the need for care to be person-centered. A systematic review found that co-design approaches are most often described in the fields of mental health, primary care, and pediatrics, and that each field is distinctive and will benefit from different implementation strategies (2). Lived experience engagement and integrated knowledge translation are also at the forefront in spinal cord injury research and practice, resulting in the recent formation of groups that are focused on bringing together people with lived experience, clinicians, and researchers to bring about change (4). Knowing that co-design approaches are impactful in any population, we encourage rehabilitation researchers and decision-makers to consider how they can best use co-design to support each unique population they support.

The articles in this research topic highlight the importance of co-design methods in developing and evaluating rehabilitation programs, educational tools, and technologies. Using a co-design approach ensures rehabilitation practices are person-centered and are meeting the needs of key stakeholders, including patients, caregivers, and clinicians, as well addressing enablers and barriers within the healthcare system. It is imperative that co-design approaches are carried out intentionally and with people with lived experience at the core, in order for the field to move forwards toward co-production. As the articles in this Research Topic primarily focused on initial development of rehabilitation programs, educational tools, and technologies, it will be important for future research to use co-design to evaluate progress and person-centred outcomes, as well as to reflect on larger impacts in service delivery models and organizational structures, which typically require a higher level of engagement.

Author contributions

JU: Conceptualization, Writing – original draft. DW: Conceptualization, Writing – review & editing. JB: Conceptualization, Writing – review & editing. JM: Conceptualization, Writing – review & editing.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Delivery of a community-based peer mentorship program for people with spinal cord injury at a rehabilitation center

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Introduction: Community-based spinal cord injury (SCI) organizations deliver peer mentorship programs in rehabilitation settings. Little is known on how these programs are delivered through the collaboration between community-based SCI organizations and rehabilitation institutions. This study aimed to identify barriers, facilitators, and collaboration processes within a SCI peer mentorship program provided by a community-based organization at a rehabilitation center.
Methods: A qualitative case study design was applied. Seven participants were recruited, including two mentees, two mentors, one program director of the community-based SCI organization, and two healthcare professionals of the rehabilitation center. Each participant completed a one-on-one interview. Data were analyzed inductively and deductively based on the Consolidated Framework for Implementation Research (CFIR).
Results: Ten factors were identified to influence the delivery of the peer mentorship program, including nine CFIR constructs. Successful delivery of the program required strong, collaborative inter-professional relationships between health professionals and community organizational staff (e.g., peer mentors) as facilitators; whereas potential cost, minimal patient needs, and limited mentor resources were found to be barriers. Engaging health professionals by initiating communications, reflecting and evaluating the program collectively with health professionals were important collaboration processes for the community-based organization to maintain effective partnership with the rehabilitation center.
Discussion: The collaboration processes and strategies to addressing/leveraging the barriers and facilitators may inform evidence-based practice to establish and optimize the delivery of SCI peer mentorship programs in various rehabilitation settings.

KEYWORDS

spinal cord injury, rehabilitation, community services, peer support, qualitative research

Introduction

Spinal cord injury (SCI) refers to any damage or lesion to the spinal cord that results in autonomic, motor, and sensory impairments and lifelong disability. After an SCI, people often begin a rehabilitation process in which they experience significant adjustment to life (1). One strategy that has been utilized to support the rehabilitation and community re-integration for people with SCI is peer mentorship (2). Peer mentorship is a form of peer interaction aiming to help individuals who share similar lived experiences adapt and thrive (3, 4). In Canada, provincial community-based SCI organizations collaborate with more than 41 hospitals and rehabilitation centers to make peer mentorship available for many Canadians with SCI (5).

Delivering peer mentorship programs in rehabilitation settings often relies on collaborations between community-based SCI organizations and rehabilitation institutions (6). Peer mentorship literature has mostly gathered insights from mentors, mentees, family members, and community organizational staff to understand characteristics and outcomes of peer mentorship programs (5, 7). However, it remains unclear how peer mentorship programs are delivered through collaborations between community-based SCI organizations and rehabilitation institutions. Additionally, the role of health professionals and their relationships with community organizational staff (e.g., peer mentors) within peer mentorship programs largely remains unknown. Without this knowledge, it is difficult to optimize the implementation of SCI peer mentorship programs within rehabilitation contexts.

Some international studies examined the integration of SCI peer mentorship programs into rehabilitation settings (8–14). For one, Cabigon et al. (2019) investigated the inter-professional collaboration between peer mentors and health professionals in delivering SCI bowel education and demonstrated the feasibility of the program at an American rehabilitation center (8). In addition, a Danish study described the process of health professionals recruiting and training peer mentors prior to the delivery of a SCI peer mentorship program (11). These two studies highlighted that the collaborative relationship between SCI peer mentors and health professionals was important to the programs. However, they focused on the development phase of the peer mentorship programs without investigating how SCI peer mentors and healthcare professionals collaborate to maintain SCI peer mentorship programs.

Theoretical frameworks in implementation science may help us understand the collaboration between rehabilitation institutions and community-based SCI organizations in delivering peer mentorship programs (15). One framework that was specifically designed for investigating the implementation and delivery of a program/service is the Consolidated Framework for Implementation Research (CFIR) (16). The CFIR organizes 39 factors (e.g., networks and communications) that influence the implementation of a program into five domains (e.g., intervention characteristics). The CFIR has been used to investigate programs/services for people with SCI (17) and allowed the researchers to examine various aspects of the programs, including relationships among the personnel involved (15, 18).

The purpose of this study was to identify barriers, facilitators, and collaboration processes within a SCI peer mentorship program provided by a community-based organization at a rehabilitation center. Framed around the CFIR, three main research questions were: (1) how was the peer mentorship program delivered through the collaborations between the community-based organization and the rehabilitation center; (2) what were the barriers and facilitators to the delivery of the program; and (3) what were the inter-professional relationships between the community organizational staff (e.g., SCI peer mentors) and the rehabilitation professionals?

Methods

Design

We applied a qualitative case study design (19), which allowed us to collect contextual information on the program and investigate how the peer mentorship program was delivered (19, 20). We situated this study within a post-positivist paradigm (21) and assumed that an external reality existed independent of our knowledge of it (i.e., modified realist ontology). Our research team consists of one retired SCI peer mentor (JC) and five researchers (AT, GB, HG, SS, and ZS) who self-identify as being non-disabled. AT, GB, HG, and SS are associate/full university professors. ZS is a senior doctoral candidate with seven years of research experience, primarily using qualitative methodologies. AT and HG have expertise in the field of implementation science/knowledge translation within the rehabilitation and disability contexts. GB, HG, SS, and ZS conducted multiple research studies on peer mentorship in various contexts, such as parasport and SCI. HG, SS, and ZS have a research focus on social participation and well-being promotion among individuals with SCI. GB is an expert in qualitative research who assisted JC, SS and ZS to critically think about the data. This combination of the diverse expertise resonates with the focus and design of the current study. Our different knowledge backgrounds and research experiences inescapably shaped how we formulated the research questions and interpreted different aspects of the SCI peer mentorship program [i.e., subjectivist epistemology; (21)].

Setting

We identified a local community-based SCI organization that offers peer mentorship programs in both the community and rehabilitation settings, including a rehabilitation center that provides services to individuals with SCI. There is no cost to patients in the rehabilitation center to participate in the peer mentorship program. The community-based organizational staff, including SCI peer mentors, are on-site at the rehabilitation center and work directly with a multidisciplinary healthcare team including occupational therapists and physical therapists. The peer mentorship is mentee-focused in that topics of the conversations can vary depending on mentees' specific needs. Peer mentorship is delivered through both (a) informal, unstructured conversations between mentors and mentees, which can happen at bedside or common areas (e.g., cafeteria) at the rehabilitation center and (b) formal, structured conversations either by information sessions delivered by mentors and rehabilitation staff or individuals, topic-focused discussion with a mentee. The mentorship relationship can also continue after in-patient rehabilitation process as mentors also provide mentorship to people with SCI living in the community. We chose to look at this program because it is recognized as long-standing and successful, with more than forty years of continuous delivery.

Participants and data collection

We recruited a purposive sample of seven participants from the community-based SCI organization and the rehabilitation center. Participants were individuals involved in the peer mentorship program with different roles, including two mentees, two mentors, one program director of the community-based SCI organization, and two healthcare professionals of the rehabilitation center (one social worker and one kinesiologist). The sample size aligned with the qualitative case study design (22). All seven participants were adults, had no cognitive impairments, and were able to communicate in English or French. Eligible healthcare professionals must have experience of interacting with a SCI peer mentor(s) during the last two years. Eligible peer mentees and mentors must have engaged in the peer mentorship program at the rehabilitation center during the last two years. This study was approved by our university research ethics board.

We provided the information on this study (e.g., purpose, research questions, procedures) and obtained participants' consent using an online consent form embedded in emails. Each participant completed a virtual, one-on-one, audio-recorded interview with the first author (ZS) using a semi-structured interview guide. The interview guide included questions selected from the CFIR interview guide tool (cfirguide.org/) and the questions were adapted to the different roles of the participants (**Supplementary Appendix A**). For example, the question "How do you feel about the intervention being used in your setting?" (CFIR construct: Knowledge and beliefs about the intervention) was adapted to "How do you feel about the peer mentorship program at the rehabilitation center?". Each interview was planned to be completed within one hour.

Data analysis

All seven interviews were transcribed verbatim, resulting in 128 pages of text. Transcripts were analyzed using a two-step (i.e., deductive and inductive) analytical approach (23). Deductively, participants' quotes that were found to be relevant to any of the 39 CFIR constructs were coded with the constructs names. Inductively, data that did not align with CFIR constructs but were relevant to our research questions were coded with a non-CFIR construct. To represent broader ideas identified within the data, all deductive and inductive constructs were examined and organized into overarching themes. The first author (ZS) conducted the deductive and inductive coding using Nvivo and had multiple discussions with the co-authors to develop the themes. Specifically, ZS coded and extracted the data relevant to the research questions using CFIR. The development of themes was an iterative process, in which ZS had multiple meetings with JC to identify the initial themes. These initial themes were then critically examined with SS, resulting in modification of the initial themes. Next, GB helped re-organize the themes and enhance the clarity in reporting the results as a critical friend. This two-step approach allowed us to identify elements relevant to the peer mentorship program based on CFIR, while also exploring information beyond CFIR constructs. Because participants had different roles in the program, interview data were first analyzed within the same type of participants (e.g., mentees) and then across the different types of the participants (e.g., mentees vs. mentors) to identify common themes (19).

Study quality

We ensured the quality of this study following the eight universal criteria named by Tracy (2010) (24), including (1) worthy topic: by clearly defining the research purpose and highlighting its relevancy to the SCI population; (2) rich rigor: by adopting the CFIR to guide the data collection and analysis; (3) sincerity: by engaging critical friends in the analysis and recognizing our subjective values influencing the interpretations; (4) credibility: by spending time building rapport with participants during the interviews and involving the author with lived experience (JC) in the data analysis. JC lives with SCI and had worked as a SCI peer mentor for over ten years. JC's input ensured the themes identified were relevant to the delivery of the peer mentorship program from their perspective; (5) resonance: by incorporating participants' quotes into the results; (6) significant contribution: by highlighting the study implications to the SCI literature and rehabilitation practice (7) ethics: by following the procedures approved by the university ethics board; and (8) meaningful coherence: by applying research methods aligning with the qualitative case study design (25, 26). A COnsolidated criteria for REporting Qualitative Research (COREQ) checklist was attached (**Supplementary Appendix B**) (27).

Results

The data were organized into three overarching themes: program characteristics, local setting and individuals, and inter-professional collaboration. These overarching themes included ten of 39 CFIR constructs identified in the deductive analysis and one inductive, non-CFIR construct (marked with *). **Figure 1** summarized the organization of the overarching themes and constructs. We adapted the names of some CFIR constructs (e.g., cost to mentees) to ensure fit in the local context and the delivery of the peer mentorship program. Participant quotes were also presented in the results.

Program characteristics

Adaptability, cost, and relative advantage were three characteristics of the peer mentorship program that were

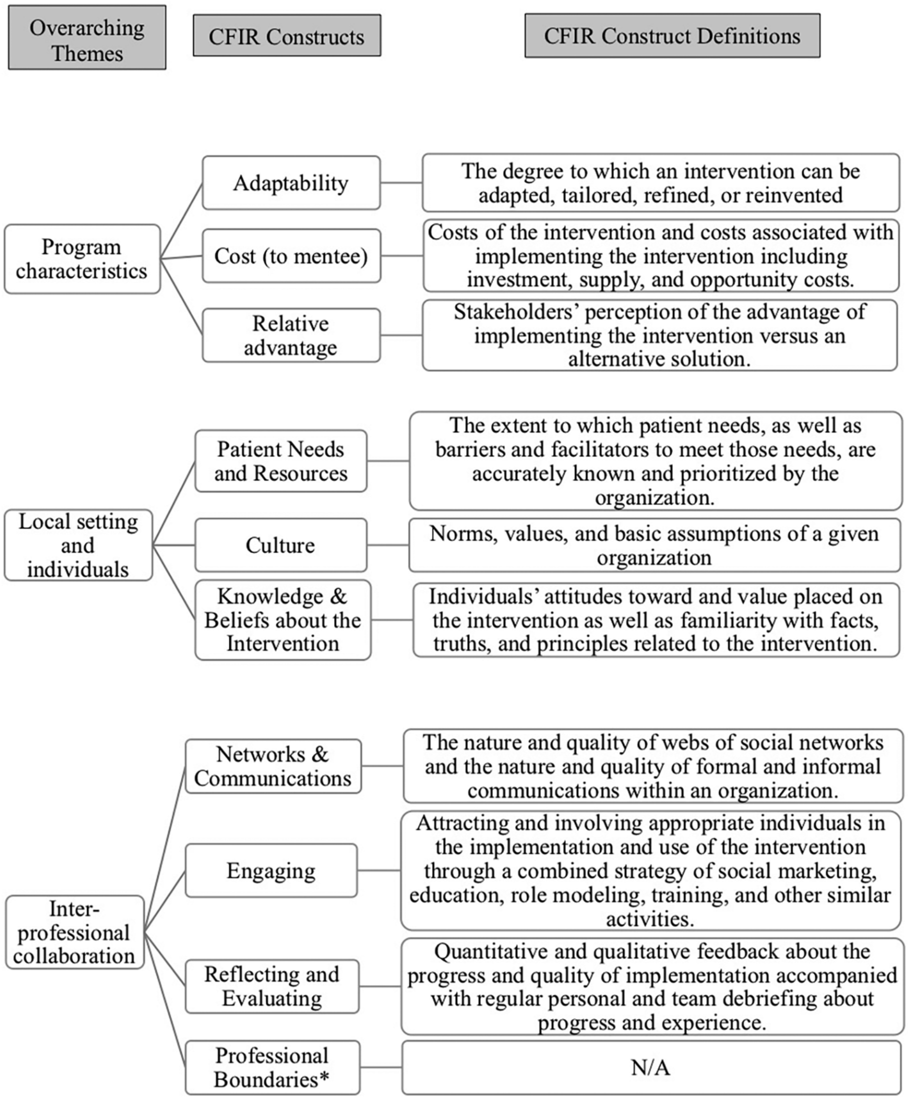

FIGURE 1
Overarching themes and CFIR constructs with its definition. * Inductive themes identified.

identified to influence the delivery of the program at the rehabilitation center.

Having a variety of methods to deliver the peer mentorship program enables the community-based organization and the rehabilitation center to adapt, tailor, refine, or reinvent the program as needed [Adaptability]. The rehabilitation center and the community-based organization typically deliver the program by creating an environment where mentors and patients interact through informal conversations. However, they also offer mentees a regular magazine, group-based coffee meetings, and a series of courses on SCI, which allows mentees to interact with peer mentorship resources that meet their needs. Furthermore, the community-based organization and the rehabilitation center made adaptations to the program during the COVID-19 pandemic by coordinating formal in-person, one-on-one meetings between mentors and mentees to maintain the delivery of the program.

> "Normally we were able to do a lot of activities in-house, at the [rehabilitation center], but we couldn't do any for a long time [during the pandemic]. The patients were [restricted] in their rooms… That's when we realized that it was so complicated to meet with the patients. We asked the nurse on the second floor to help us plan formal meetings in a local area with each patient with spinal cord injury. As I said, if we don't do that, I would say we're going to lose so many people, (and) we can't do that. So, it's the way we adapted to the new situation." —Julie (program director of the community-based organization)

Despite the fact that the current peer mentorship program is free for patients with SCI at the rehabilitation center, any potential monetary cost to access the program can become a possible barrier for patients with SCI to participate in the program [Cost to mentee], as Jack (mentee) said:

> "You can get all the information on the Internet. Anyways, you know? … I can read all over the Internet and there's forums, you know, there's Christopher Reeves Foundation. There's all kinds of stuff where I can talk to many experienced paraplegics on the Internet. Yeah, so for me, there's no point in paying for [peer mentorship] at all… If they were to charge people for their services, I would not be… I'd rather pay for medical service."

Finally, the peer mentorship program was found to be a valuable addition to regular rehabilitation services [Relative advantage]. The health professionals noted the peer mentors were able to provide disability-specific tips and helpful suggestions based on their lived experience with SCI. These suggestions helped the health professionals supplement their medical and therapeutic recommendations. As Anna (social worker) noted:

> "We are professionals, we didn't go through that [living with SCI]. They [mentors] really lived the situation, because some patients will say [to us] 'you didn't live it' and they are right, we are here to accompany, we didn't really live it, whereas the mentors have really lived the situations."

Local setting and individuals

The delivery of the peer mentorship program related to three CFIR constructs, focusing on patients' needs, a positive organizational culture within the local rehabilitation center, and health professionals' adequate knowledge and beliefs about peer mentorship.

A strong need for peer mentorship identified among the SCI patient clientele at the rehabilitation center appears to facilitate the delivery of the program. Because the community-based organization partners with multiple hospitals and rehabilitation centers in the region, it tends to allocate mentor resources and prioritize institutions with a larger SCI clientele and/or a greater patient need for the peer mentorship program [Patient Needs and Resources]:

> "In most settings, they don't have a lot of people with SCI there. And there are no centers across our province other than the [rehabilitation center] where patients are onsite with a [SCI] group… We know that there's always 20 patients, so we have people in house all the time because we're going to be crossing and seeing people at the center where you go in once or twice a week. You can't hire somebody who's going to work two hours a week or three hours a week and say, 'Be there on Tuesday from three to four and Thursday from ten to eleven.' In those situations, we tend to typically offer services more personalized where somebody will talk over the phone, you know, when you're interested in talking. But having somebody on site is not always feasible." — Jean (mentor)

Second, an organizational culture that values new changes and is willing to adapt to changes at the rehabilitation center was another facilitator for the delivery of the peer mentorship program [Culture]. In the current peer mentorship program, the program director of the community-based organization had experienced different organizational cultures within the rehabilitation center by working with health professionals over many years. She highlighted the impact of a recent change in staff that created a more positive organizational culture and resulted in improved outcomes of the peer mentorship program.

> "People who retired and the new people who came in found that there was a culture change. It's really healthier. We're giving a very positive input to the patients."—Julie (program director of the community-based organization)

Third, the positive attitudes toward and the value placed on the peer mentorship program by the health professionals were identified as key facilitators to the delivery of the program [Knowledge and Beliefs about the Intervention]. The ongoing interactions with the mentors helped the health professionals expand their knowledge on SCI peer mentorship and thus develop a strong commitment to collaborating with the mentors.

> "We learn a lot from their [mentors] experience…If we need to realign our thinking, our vision, it's always a question we ask [mentors], 'what you had wanted to change in rehabilitation, what we could have done better, and how you would have liked it if we had talked about [certain] things.' To have this feedback from them [mentors] is very important for us to be able to align our work and to be in the right direction." — Nada (kinesiologist)

Interprofessional collaboration

The peer mentorship program requires a cohesive interprofessional collaboration that consists of engaging the health professionals in the program, as well as evaluating and reflecting on the delivery of the program. Interprofessional collaboration can also be built by establishing strong communication channels and clear boundaries between the health professionals and the community-based organizational staff, particularly the mentors.

One mechanism that appeared to build inter-professional collaboration is having quality social networks and communications between the mentors and the health professionals [Networks & Communications]. In this case, the peer mentors have an office at the rehabilitation center and share workspace with the health professionals. This proximity creates opportunities for frequent, informal communications between the health professionals and the mentors, while facilitating resolution of misunderstandings around patient care:

> "The mentors are on the same floor as us, they are practically in our offices so we get to see them. It's [the communication] quick, it's easy, it's efficient. They are also often around the floor for a variety of reasons, so we can interact with them as they pass… Sometimes it [the communication] can be informal, like in the hallway and we bump into a member of [community-based organization]. Sometimes something happens where they [mentors] might have made a suggestion, such as about an adjustment or type of wheelchair, but as we know the client, and our recommendation might be a reason that's not so obvious to someone else, so we might have to talk about why we suggested what we did vs. what they thought." —Nada (kinesiologist).

Another mechanism that the community-based organization strengthens the interprofessional collaboration is attracting and involving the health professionals in the peer mentorship program by helping them understand mentors' roles and benefits of the peer mentorship program [Engaging]:

> "They [health professionals] have to know the [SCI] organization well, the [healthcare] team has to understand the importance of that [mentorship]. It must be well explained to the teams that are giving the care: what is the role of a peer mentor and what they bring to people. You [health professionals] really must understand that as a base. Once they understand that, they're going to be more motivated to put in place a service like [peer mentorship], and they're going to be able to see how it can help them in their interventions." —Julie (program director of the community-based organization)

Consistent evaluation and reflection on the progress and quality of the peer mentorship program was another important process of the interprofessional collaboration [Reflecting and Evaluating]. Within the current program, the program director of the community-based organization has been taking an integral role in tracking the progress and quality of the peer mentorship program. However, a team approach through collaborating with the health professionals and the mentors is needed due to emerging challenges in delivering the program. As these two quotes below demonstrated,

> "I do all the budgeting, I hire the people, all the work of a manager… I make sure that they [mentors] are present at the [rehabilitation center]. I make sure that as much as possible we meet all the people who come to the [rehabilitation center], obviously those with an SCI… Of course, when there are new employees, new senior integration mentors, I make sure that the [rehabilitation center's] management is aware of this, that they [the mentors] have training… We are challenged in different ways. We arrive and sometimes the clientele is really older so we have to adapt our intervention a little bit, the activities we offer to succeed in getting people interested." —Julie (program director of the community-based organization)

> "I think we [the health professionals and the community-based organizational staff] could have even more discussions [on letting patients participate in the peer mentorship program]. I think sometimes there might be disagreement between us [the health professionals] and the mentors, [because] in the rehabilitation environment where we [the health professionals] have to be a little more careful with new spinal cord injuries [patients]. Sometimes [the health professionals believe] they are not ready to be sent to an activity of [the community-based organization] because they may not have someone to help them transfer." —Nada (kinesiologist)

While the interprofessional collaboration is key to the peer mentorship program, maintaining professional boundaries between the health professionals and the community-based organizational staff is also important [Professional Boundaries*]. As Betty (mentor) mentioned, "We are not registered in their rehabilitation program. We are completely independent. Yes, we collaborate with the health specialists, but we remain an independent entity". In this case, the rehabilitation center and the community-based organization have an agreement that explicitly outlines the boundaries regarding the mentors' access to patient confidential information. Although the agreement does not include all aspects of the mentors' responsibilities, it helps the health professionals and the mentors understand and adhere to their roles in patient care:

> "We [mentors] must not interfere with the role of social workers in the rehabilitation center. For example, an occupational therapist should not feel challenged in what she does in comparison to a senior mentor in the center. If this happens, we have to resolve the situation. Everyone has to know their place. So that's really important… We never directly give the patient the clinical judgment, that's being a professional." —Julie (program director of the community-based organization)

Although the professional boundaries were clear to the mentors and the health professionals, these boundaries might be blurry for patients. Patients may expect clinical guidance from mentors and can potentially create difficult situations during their interactions with mentors and/or health professionals, as Frank (mentee) said: "I was putting them [mentors and health professionals] together. They all did the same thing. That is to say, answer my questions and enlighten me on the various aspects of reduced mobility. On both sides, I would say that they did a lot on the same job. For me the plus side is that it [the mentor] brings sports into our exchanges." Patients' confusion in these roles might impede their participation in the peer mentorship program because they might not perceive the benefits of engaging with mentors.

Discussion

The purpose of this study was to identify barriers and facilitators to the delivery of the peer mentorship program provided by a community-based SCI organization at a rehabilitation center and characterize the collaboration processes between the community organizational staff and the health professionals. We gathered multiple perspectives from the individuals directly involved in the program, including peer mentorship program director, peer mentors, mentees, and health professionals. In addition to the barriers, facilitators, and collaboration processes identified, our study highlighted multiple strategies that the rehabilitation center and the community-based organization have taken to address/leverage these barriers/facilitators. The strategies may inform collaborative processes needed to establish a partnership between rehabilitation institutions and community-based organizations as per this peer mentorship program.

In alignment with previous studies using the CFIR in a healthcare context (28, 29), the barriers and facilitators identified in this study were found to influence the delivery of the peer mentorship program, including adaptability, cost, relative advantage, knowledge and beliefs about the intervention, culture, networks and communication, patient needs and resources, engaging, and reflecting and evaluating. The constructs identified covered all five CFIR domains and demonstrated a full breadth of the results. For example, the collaborative networks and communication between the mentors and the health professionals were found to be key for the program, which aligns with past research as being one of the most frequently used CFIR constructs (29). Our results enrich the literature by identifying how peer mentors and health professionals strengthen their network and communication. For instance, sharing workspace, having informal conversations, and maintaining clear professional boundaries were strategies used by the mentors and the health professionals within the current peer mentorship program. Future peer mentorship programs should consider these collaboration and networking strategies to ensure the success of program implementation.

Peer mentorship programs within rehabilitation settings often target specific health outcomes for people with SCI (e.g., self-efficacy) (9), while the program in our study had an objective of promoting broader outcomes such as social and community re-integration. The community-based organization's objective closely aligns with the health professionals' goal of facilitating patients' transition from rehabilitation to community. This alignment has contributed to the consistent engagement in the program for both organizations. Creating a shared vision is important for organizations to work together, whereas it is often challenging (30). Carrying out group activities that can encourage staff members to openly share their perspectives may help organizations develop a shared vision (31). These group activities may also allow staff from community-based organizations and rehabilitation institutions to share decision-making in defining goals and structure of the peer mentorship program prior to its delivery.

Communication among staff members tends to be an important aspect to successful implementation of services/programs across healthcare contexts (32, 33). Similarly, the "networks & communication" construct was identified as a facilitator in our study as the relationship between the mentors and the health professionals was highly collaborative and interactive. Other rehabilitation institutions might experience more challenges in maintaining constant team communication, particularly for those with a larger team or a culture with low expectations for communication (34). Within the current program, an office space for mentors embedded into the rehabilitation center enhances communication between mentors and rehabilitation staff. When a physical space is not possible, leaders of community-based organizations and rehabilitation institutions should foster communication among staff members by encouraging team discussions, forming a coalition/learning group, and/or identifying an opinion leader who can oversee the implementation (35).

Interprofessional collaboration has received growing attention in healthcare (maybe add a reference here as an example?). In our study, "networks and communication" and "professional boundaries" were the two largest constructs identified in terms of data volume. The interprofessional relationship between the mentors and the health professionals was interpreted as a key aspect of program implementation and maintenance. In alignment with previous research, the interprofessional collaboration between the mentors and the health professionals has resulted in multiple benefits, including personal and professional growth, as well as good work efficiency (36, 37). Additionally, because the community-based organization prioritizes delivering peer mentorship in-person, the health professionals were able to help the mentors build connections with patients and create mentor-mentee meeting opportunities. Therefore, community-based organizations and rehabilitation institutions should enhance their staff members' skills in interprofessional collaboration in order to strengthen collaborations at an organizational level, including how to maintain professional boundaries (38, 39). Although establishing and maintaining professional boundaries is often challenging in healthcare practice (38, 40), the roles of peer mentors and health professionals appeared to be well defined by the formal agreement within the current peer mentorship program. Clear boundaries can ensure the quality of mentor-mentee relationships and mentors' well-being in a long term (6, 41).

Another important collaboration process that can be challenging for community-based organizations was engaging and building buy-in among health professionals prior to the program delivery. Frequent staff change can hinder the process of engaging health professionals in the peer mentorship program (42). To address these barriers, community-based organizations can identify a local "champion"/"opinion leader" who can influence health professionals' attitudes and beliefs (43, 44) Furthermore, program evaluation over time is deemed to be necessary for delivery sustainability. For programs in the early phase, assessment can focus on appropriateness, feasibility, and accessibility (45). For long-standing programs, tracking the impacts on people with SCI may be a priority (7).

Limitations

First, we were only able to recruit two health professionals from the rehabilitation center during the COVID-19 pandemic, although there might be multiple other health professionals who were directly or indirectly involved in the peer mentorship program. The two recruited health professionals might have a favorable opinion about the peer mentorship program as they consented to participate in this study. However, obtaining the perspectives from the peer mentorship program coordinator, the mentors, and the mentees still enabled us to capture a broad picture of individuals actively involved in the program. Another limitation was that we did not apply the updated version of CFIR (46) because we collected and analyzed the data prior to the publication. However, our application of the original version of CFIR was found to be appropriate given that the facilitators, barriers, and collaboration processes were identified based on the original CFIR. Initial coding was conducted by the first author (ZS) individually. Engaging co-authors to develop and critique the themes was conducted to strengthen to rigor of our analyses.

Conclusions

Using the CFIR to guide the data collection and analysis, we identified multiple barriers, facilitators, and collaboration processes to delivering the peer mentorship program within the local rehabilitation center. Our results may help other community-based SCI organizations and rehabilitation institutions develop, maintain, and optimize peer mentorship programs in various rehabilitation settings. Community-based SCI organizations and rehabilitation institutions may enhance interprofessional collaborations between organizational staff (e.g., peer mentors) and health professionals by creating shared workspace, facilitating informal conversations, and establishing professional boundaries.

Data availability statement

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by The Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal Research Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

ZS: Conceptualization, Data curation, Formal Analysis, Investigation, Methodology, Project administration, Resources, Software, Visualization, Writing – original draft, Writing – review & editing, Funding acquisition. JC: Formal Analysis, Investigation, Methodology, Validation, Writing – review & editing. GB: Conceptualization, Formal Analysis, Methodology, Supervision, Validation, Writing – review & editing. HG: Conceptualization, Formal Analysis, Methodology, Validation, Writing – review & editing. AT: Conceptualization, Formal Analysis, Methodology, Validation, Writing – review & editing. SS: Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2023.1296505/full#supplementary-material

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Co-designing solutions to enhance access and engagement in pediatric telerehabilitation

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Introduction: Prior to the COVID-19 pandemic, children's therapy appointments provided by Ontario's publicly-funded Children's Treatment Centre (CTCs) primarily occurred in-person. With COVID-19 restrictions, CTCs offered services via telerehabilitation (e.g., video, phone), which remains a part of service delivery. CTC data shows that families experience barriers in attending telerehabilitation appointments and may need supports in place to ensure service accessibility. Our study aimed to co-design innovative solutions to enhance access and engagement in ambulatory pediatric telerehabilitation services. This manuscript reports the co-design process and findings related to solution development.
Methods: This research project used an experience based co-design (EBCD) approach, where caregivers, clinicians and CTC management worked together to improve experience with telerehabilitation services. Interview data were collected from 27 caregivers and 27 clinicians to gain an in-depth understanding of their barriers and successes with telerehabilitation. Next, 4 interactive co-design meetings were held with caregivers, clinicians and CTC management to address priorities identified during the interviews. Using qualitative content analysis, data from the interviews and co-design meetings were analyzed and findings related to the solutions developed are presented.
Findings: Four topics were identified from the interview data that were selected as focii for the co-design meetings. Findings from the co-design meetings emphasized the importance of communication, consistency and connection (the 3C's) in experiences with telerehabilitation. The 3C's are represented in the co-designed solutions aimed at changing organizational processes and generating tools and resources for telerehabilitation services.
Discussion: The 3C's influence experiences with telerehabilitation services. By enhancing the experience with telerehabilitation, families will encounter fewer barriers to accessing and engaging in this service delivery model.

KEYWORDS
childhood disability, experienced based co-design, health service research, pediatric telerehabilitation, service access, service engagement

1. Introduction

In 2006, 174,810 Canadian children aged 5–14 years had a disability as per the Participation and Activity Limitations survey criteria (1). According to a report released by Statistics Canada in 2022, 13.5% of Canadian children aged 0–14 were reported to experience at least one activity limitation as a result of a difficulty or long-term condition (e.g., mobility, learning, emotional/psychological) (2). Rehabilitation services help children with disabilities achieve functional outcomes and participate in their social environments (3–5). Annually, publicly-funded Children's Treatment Centres (CTCs) in the Canadian province of Ontario provide over 750,000 rehabilitation visits to children (ages 0 to age of secondary school exit) and their families (6). These rehabilitation services include a combination of occupational therapy (OT), physical therapy (PT), speech-language pathology (SLP) and social work (SW) services. Some CTCs also employ Board Certified Behaviour Analysts (BCBA) and Instructor Therapists (IT) to provide services to autistic children. The term clinician is used throughout this paper and could refer to a care provider from any of the previously mentioned disciplines.

CTCs provide ambulatory services based in treatment centres to address home and community goals; however some also provide services in the school setting. Prior to the COVID-19 pandemic, CTC appointments primarily occurred in-person. COVID-19 restrictions limited access to in-person rehabilitation services and children's rehabilitation service providers quickly pivoted to supporting families using telerehabilitation platforms (7). Prior to the COVID-19 pandemic it is estimated that only 4% of pediatric care clinicians used telerehabilitation; this number drastically increased to 75% during the pandemic (7). Given the rapid uptake of telerehabilitation during the pandemic, there have been calls to consider its potential to be integrated into a hybrid service model, that takes into account reported benefits of offering a combination of in-person and telerehabilitation services (7, 8).

Telerehabilitation is defined as therapy occurring remotely over a telecommunication platform such as telephone or video conferencing (9). Increasingly, telerehabilitation services are being provided by allied health clinicians and are proposed as a solution to barriers encountered when accessing in-person rehabilitation services, such as the time and cost associated with travelling to appointments (7, 10). In a 2023 systematic review examining the effectiveness of telerehabilitation in children with developmental disabilities, telerehabilitation was found to be more effective when compared to no treatment for outcomes such as functional performance, hand function, visual perception, and behaviour or as effective when compared to no treatment (i.e., waitlist) and usual treatment, respectively (11). For outcomes such as, self-efficacy, self-control and social skills, telerehabilitation was found to be as effective when compared to usual treatment (11). In autistic children, telerehabilitation was found to be more effective than in-person services across 85% of outcomes and most importantly, telerehabilitation was never found to be less effective or to cause harm (11). This evidence of effectiveness aligns with findings from another systematic review that described telerehabilitation as an effective approach to supporting the development of adaptive skills in children with multiple disabilities (12). The benefits and challenges of telerehabilitation in outpatient pediatric rehabilitation services during the COVID-19 pandemic have been described and it is recommended that service organizations address barriers to optimize the effectiveness of this model of care (13).

Evidence demonstrates that therapy outcomes and experiences are enhanced when families are actively engaged with the services they receive (14–16). Family engagement in therapy is supported through a shared understanding of expectations, collaboration and positive relationships with therapists (15, 17). To date much of the telerehabilitation literature examines its effectiveness (11, 18, 19) and the acceptability of this service model from the caregiver perspective (7, 20), however qualitative research has started to explore parent engagement in telerehabilitation as it relates to the parent-therapist relationship (10). In 2022, a qualitative systematic review described engagement in early intervention telerehabilitation for young children with developmental disabilities and provided recommendations to establish and maintain engagement with these services (21). Despite this emerging evidence related to engagement in telerehabilitation, little is known about whether telerehabilitation can assist families in attending appointments and improve engagement in their child's therapy. The Phoenix Theory of Attendance, Participation and Engagement (the Phoenix Theory) has provided substantive knowledge regarding the barriers families experience accessing, participating and engaging in CTC services when offered in-person (15). This theoretical framework and associated research findings have been used successfully at our partner CTC (KidsAbility) to inform organizational policies and services affecting families who miss in-person appointments to reduce barriers to service access and engagement.

Missed appointments are defined as appointments missed without prior notification to the CTC and have been problematized as inefficiently using clinician time and organizational resources and may impact therapeutic outcomes (22, 23). For this project, we partnered with KidsAbility Centre for Child Development (KidsAbility), an Ontario CTC to explore missed telerehabilitation appointments, defined by KidsAbility as appointments occurring by phone or video. Since commencing with telerehabilitation services in March 2020, KidsAbility continues to report high numbers of missed appointments. From 2022 to 2023 14% ($n = 1{,}652$) of telerehabilitation appointments were missed, which was comparable to 15% (10, 349) of in-person appointments that were missed at KidsAbility. A total of 456 telerehabilitation appointments were missed without prior notice, limiting opportunities for clinicians to effectively use that client time. These metrics indicate that families experience barriers to service use, even when services are offered via telerehabilitation.

The aim of this project was to co-design innovative solutions that will enhance access and engagement in telerehabilitation in the context of publicly-funded pediatric rehabilitation for children with disabilities. We have collaborated with KidsAbility and a parent-partner to address the following research question: What co-designed solutions can be developed to improve families' access and engagement in pediatric telerehabilitation services? The scope of this paper focuses on describing the co-design process and reports findings related to the solutions developed.

2. Materials and methods

2.1. Study design

Experience based co-design (EBCD) is a highly collaborative approach to research that focuses on the lived experience of service users and service providers to develop innovative solutions to health service issues (24, 25). EBCD necessitates authentic engagement with invested parties (caregivers, clinicians, health service organizations) throughout research development, implementation and evaluation (25, 26). With its origins in design sciences, EBCD has been proposed as an approach to create or modify health service experiences through integrating patients as partners in service design projects (27). EBCD has been utilized to design health services in the public sector with the potential for authentically engaging vulnerable populations (24, 28–30).

EBCD prioritizes collaboration, partnership between invested parties and researchers, lived experience as expert knowledge, capacity building and creativity in generating solutions (25, 27, 29). Integrating qualitative methods, this project is guided by the six stages of the EBCD approach proposed by Bate and Robert (2007). For the purpose of this project, the stages of EBCD were conceptualized as: (1) setting up the project; (2) engaging clinicians and gathering their experiences; (3) engaging families and gathering their experiences; (4) co-design meetings; (5) sustain co-design engagement and implement change; (6) celebrate and evaluate changes to health service.

Stages 1 through 4 all contribute to the overall co-design process. This paper will provide a detailed account of the methods and findings for the stage 4 co-design meetings, when the co-designed solutions were developed. Stages 1 through 3 will be reviewed briefly with a focus on how they informed the stage 4 co-design meetings. **Table 1** provides a summary of key information linked to stages 1 through 4 of the co-design process as related to this project. Ethical approval for this study was received by the Hamilton Integrated Research and Ethics Board (project #14235).

2.2. Study context

The study context is described in detail to aid readers in determining the transferability of our findings to other settings. This study was completed at KidsAbility in Ontario, Canada. KidsAbility has 6 sites (5 permanent locations and 1 rural satellite clinic) providing publicly-funded children's rehabilitation services across a highly multicultural region that includes both urban and rural communities. In response to restrictions associated with the COVID-19 pandemic, KidsAbility pivoted to providing telerehabilitation services, which continue to be offered as part of a hybrid service model combining both in-person and virtual visit options. A partnership was formed with KidsAbility for this project because author MR worked there as a clinician, facilitating a deep understanding of the culture, services, provision of telerehabilitation and characteristics of the families served. Author MR examined the impact of her dual role as a clinician and a researcher who is closely connected to the study context by engaging reflexively with literature on this topic, keeping reflective memos and by debriefing with the steering committee, to ensure multiple perspectives were included in all project decisions.

2.3. Stage 1: setting up the project

The need to reduce barriers in accessing telerehabilitation services was identified from the results of a survey administered by KidsAbility in 2020. Survey results aligned with concerns that were raised by the KidsAbility's parent advisory committee

TABLE 1 Summarizing stages 1 through 4 of co-design process.

	Experience Based Co-Design Process			
	Stage 1—setting up the project	Stage 2—engaging caregivers and gathering their experiences	Stage 3—engaging clinicians and gathering their experiences	Stage 4—co-design meetings
Purpose	Establish channels to advise project directions from the perspective of multiple invested parties	Understand experiences with receiving telerehabilitation at KidsAbility	Understand experiences with providing telerehabilitation at KidsAbility	Co-design solutions to enhance telerehabilitation experience
Participants	Steering committee: parent ($n = 1$), clinicians ($n = 2$) researchers ($n = 4$), KidsAbility Parent Advisory Committee: (PAC) ($n = 6$ members consulted)	Caregivers ($n = 27$)	Clinicians ($n = 27$)	Caregivers ($n = 9$), clinicians ($n = 12$), managers ($n = 3$) Groups ranged from 5 to 7 participants
Data collection	Parent Advisory Committee: Single point of consultation during project conceptualization Steering committee: Consultation throughout the project to develop the research question, methods, and participate in data collection and analysis	Interviews	Interviews	In-person co-design meetings ($n = 3$) virtual codesign meeting ($n = 1$)
Outcome(s)	Research methods and findings tailored to KidsAbility practice context	Touch point identification to inform co-design meetings	Touch point identification to inform co-design meetings	3Cs (communication, consistency, connection) impacting telerehabilitation experience and co-designed solutions to improve access and engagement in telerehabilitation

related to families' equitable access and engagement in telerehabilitation services. The parent advisory committee is a voluntary committee of caregivers whose children are currently engaged with services at KidsAbility or had received services in the past. Open discussion forums were held with the parent advisory committee to guide the development of the research question, objectives, and to identify meaningful indicators of access and engagement in telerehabilitation services. Insights from six committee members emphasized the importance of diverse family representation in the study including geography, ethnicity, family composition, and characteristics of the child (e.g., severity of needs and age) presuming that barriers to telerehabilitation would vary according to these factors.

A multi-disciplinary steering committee including four interdisciplinary researchers, two individuals with clinical experience providing telerehabilitation services and a parent whose child had received KidsAbility services was assembled. The steering committee meets regularly and is responsible for collaboratively participating in all aspects of the project, including but not limited to defining the research question, establishing methods for data collection, engaging in data collection, facilitating co-design groups, supporting data analysis and contributing to knowledge sharing activities (e.g., presentations, manuscript preparation).

2.4. Stages 2 and 3: engaging clinicians/caregivers and gathering their experiences

The data from semi-structured interviews completed with 27 caregivers and 27 clinicians about their experiences with telerehabilitation will be reported in a separate paper. These interviews informed the co-design process by eliciting the touch points, which are emotionally powerful and memorable highs and lows of engaging in telerehabilitation (27). Interviews were completed virtually and audio recorded using the Zoom platform (31) between October 2022 and December 2022. Inductive qualitative content analysis was completed to identify, describe and visualize the touch points. Following this analysis, MR led the steering committee in a journey mapping elicitation activity where Google Jamboard was used (32) to further categorize touch points based on commonalities and to map them onto a timeline representing the journey of a telerehabilitation appointment (i.e., time leading up to the appointment, during the appointment and follow up from the appointment). The purpose of this task was two-fold. First, mapping the touch points provided a visual depiction of when participants were experiencing the touch points during their telerehabilitation journey. Second, through collaborative discussion, journey mapping allowed for the prioritization of the touch points that would be carried forward into the co-design meetings aimed at developing solutions to enhance the telerehabilitation experience. An audit trail was kept to document decisions made by the steering committee during all data collection and analysis phases of this project. Analytic memos documenting reasoning for decisions and directions taken during this project were kept by author MR. Peer debriefing was practiced during monthly meetings with the steering committee to guide project related decisions.

2.5. Stage 4—co-design meetings

2.5.1. Sampling

Caregivers with children who received telerehabilitation services from KidsAbility in the previous 12 months were recruited by self-referral using established communication channels between KidsAbility and families (e.g., KidsAbility's social media platforms, website and email list). Direct emails to clinical staff and advertising in the internal staff newsletter were used as additional strategies to recruit clinicians via self-referral who had provided telerehabilitation service KidsAbility in the previous 12 months. The timeframe of 12 months was selected for both caregivers and clinicians to ensure that they had relatively recent experiences receiving or providing telerehabilitation. The desire was for experiences to be representative of the current status of telerehabilitation service provision and not of that which was provided when CTCs were required to pivot to this unfamiliar service model in response to the COVID-19 pandemic in March 2020.

Participants were recruited to take part in one of the four co-design meetings. Given that our aim was to maximize the diversity of perspectives, caregiver and clinician participants did not have to complete an interview in stages 2 or 3 to participate in the stage 4 co-design meetings. In addition to clinicians and caregivers, managers who directly supervised staff providing telerehabilitation services were also recruited for this stage of the co-design process. Managers were recruited through the same internal communication channels as clinical staff (i.e., internal newsletter, email). Although managers did not have direct experience providing telerehabilitation services at KidsAbility, co-design approaches recommend including those in positions to influence service delivery decisions (25). Therefore, our steering committee felt it was important that managers be included in the development of solutions to the touch points identified in stages 2 and 3. Including managers ensured their voice was heard in the process and encouraged investment in the co-designed solutions, enhancing implementation and sustainability efforts. Recruitment for this phase of the project launched in February 2023 and closed April 2023.

2.5.2. Participants

Sixteen caregivers were enrolled into this phase of the study and 9 attended a co-design meeting as planned (one parent could not be reached to schedule into a meeting, one parent cancelled prior to the scheduled meeting and 5 did not give prior notice that they would not be attending). Demographic data were collected using a form developed in Research Electronic Data Capture (REDCap) (33). Caregivers were recruited from 3 of 6 KidsAbility sites, with one family reporting that they lived rurally. Seven families identified that the primary language spoken in the home was English, while the two other families spoke either Telugu or Bilen. All families identified having access to reliable internet at home. Seven mothers and 2 fathers participated in the co-design meetings and all families identified having one child who received telerehabilitation services from KidsAbility. Children of the caregiver participants ranged in age, 0–3 years old ($n = 4$), 4–7 years old ($n = 4$) and 12–15 years old ($n = 1$). Caregivers identified their children as having the following diagnoses: speech and language delay ($n = 5$), global developmental delay ($n = 3$), autism spectrum disorder ($n = 2$), cerebral palsy ($n = 1$), and other (sensory processing differences, epilepsy) ($n = 2$). Two families reported that their child had more than one diagnosis. Six families engaged in telerehabilitation appointments with SLP, 5 with OT, 2 with PT, 2 with SW and 1 family was unsure of the clinical discipline they interacted with. Four families received telerehabilitation from more than one clinical discipline and all families reported that these were individual sessions with their child. One family indicated receiving both group and individual therapy.

Thirteen clinicians enrolled and 12 participated in a co-design meeting (one clinician was unable to attend due to a change in their availability). Representation of clinical disciplines included SLP ($n = 7$), CDA ($n = 2$), IT ($n = 1$), OT ($n = 1$) and PT ($n = 1$). Years of clinical experience of the clinical participants ranged from 1 to 5 ($n = 5$), 6 to 10 years ($n = 4$) and 11 to 15 years ($n = 3$). Six clinicians identified having 0 to 2 years of experience providing telerehabilitation services and 6 identified having 3 to 5 years of experience. Three managers were enrolled and participated in a co-design meeting. The participating managers reported having at least 16 years of clinical experience in their discipline, while management experience ranged from 1 to 5 years ($n = 1$), 6 to 10 years ($n = 1$) and 11 to 16 years ($n = 1$). Between clinicians and managers, participants represented all clinical programs at KidsAbility (e.g., early intervention services, school aged and school-based rehabilitation services, autism services, and specialized services such as augmentative communication services).

2.5.3. Data collection and analysis

Four co-design meetings, each two hours in length, were conducted between April 2023 and May 2023. Three of these meetings were conducted in-person, at three different KidsAbility sites and one was held virtually over Zoom (31) to accommodate those who were unable to attend in-person. Three of the four co-design meetings had caregiver, clinician and management representation. One in-person group did not have a manager participate. All sessions were audio and video recorded to facilitate subsequent transcription and analysis of the data. Authors MR and MNP co-facilitated all meetings alongside a parent facilitator. All parent facilitators had experience being members of a research team and/or facilitating group discussions with other caregivers. The parent co-facilitator worked closely with the caregiver participants to validate their experiences, encourage idea sharing and create a safe space for collaboration. Transportation and language interpretation services were made available in all phases of this project to enhance the accessibility of participation.

The co-design meetings were run in an interactive focus group format. Each co-design meeting focused on a different touch point that emerged from interviews. The aim of the co-design meetings was to bring multiple invested parties (caregivers, clinicians and management) together to collaboratively develop solutions and prototypes for the touch points impacting experiences with telerehabilitation at KidsAbility. Each co-design meeting was divided into three sections: (1) introductions, orientation to the touch point and aims for the session; (2) solution development; and (3) prototype development. The COMPASS for Relational Safety in Co-design/Production and the corresponding MAPS framework guided the structure of the group to work toward creating an atmosphere where all participants felt comfortable collaborating toward a common goal (34).

(1) Introductions, orientation to the touch point and aims for the session—The meeting began with introductions and an ice breaker activity in the hopes of creating relatable moments between participants (34). Guidelines for engagement were discussed to ensure all participants had a common understanding of suitable ways to engage in discussion and idea sharing. Participants were oriented to the touch point of focus for their meeting using multimedia tools. These tools included an animated video depicting the positives aspects of telerehabilitation services as reported by caregivers and clinician during the interviews as well as a poignant image with a voice over of a caregiver and clinician speaking about the negative aspects of telerehabilitation in relation to the touch point. Once familiar with the touch point, the aims of the session and the activities were reviewed with the participants.

(2) Solution development—Next the participants were presented with the task of developing solutions to the touch point. A modified 1-2-4-all Liberating Structure was used to guide this activity whereby participants started with independent idea generation, shared ideas in small groups and then engaged in a full group discussion about the favourite ideas generated by each small group. Liberating Structures are a set of interactive methods used to facilitate inclusive engagement of multiple and diverse voices working toward a collective purpose and have been used to support change in health services research (35–37). Specifically, the 1-2-4-all Liberating Structure is an effective way to engage multiple people at the same time to generate ideas (36). Every participant was given a sticker to place beside their favourite idea and the idea with the most stickers was brought forward for further discussion in the prototyping phase.

(3) Prototype development—The idea that was prioritized for prototyping was the focus of section three of the meeting. Participants broke into their small groups and used arts-based methods (e.g., paper, sticky notes, markers, coloured stickers, etc.) to design low fidelity prototypes of what it would look like to implement the prioritized solution into the policy and practices of KidsAbility. Tools available in Jambord (32) (e.g., white board, sticky notes, labels) were used to support prototyping during the virtual meeting. Low fidelity prototyping is a technique described in the EBCD process (27). The participants then reconvened as a full group to provide verbal descriptions of their prototypes.

The aim of data analysis during stage 4 of the co-design process was to describe the solutions prioritized and the prototypes developed by participants in the co-design meetings. Data from the co-design meetings were analyzed using inductive qualitative content analysis as described by Elo & Kyngas (38). Data sources from the co-design meetings included sticky notes from the idea generation phase, the prototype materials (e.g., sketches) and transcripts from group discussions. Transcripts were read multiple times by author MR to make sense of the data. During a collaborative analysis session, authors MR and MP engaged in open coding and categorization of data from the transcripts, sticky notes and prototypes. Additionally, transcripts were coded and categorized by author MR using NVivo software (39) through line by line reading of the transcripts. Data from the transcripts contextualized the arts-based data (sticky notes and prototypes) by integrating explanations of the participants who generated the ideas. Data across all four focus groups were analyzed to explore similarities and differences in the solutions developed as well as potential opportunities to blend similar prototypes. Categorized was synthesized into narrative form by authors MR and MP via the use of analytic memos. Iterations of the narrative synthesis were reviewed during peer debriefing meetings between author MR and senior researcher MP. Member checking with the participants in the co-design meetings was not completed, however the categories and synthesis were reviewed and validated by authors JLL and CL through the caregiver and clinician lens respectively and feedback was incorporated into the findings. Their feedback did not result in altering the coding or categorization structure.

3. Results

The results of this research are described in four sections below. First, touch points identified from the interviews completed with caregivers and clinicians in stages 2 and 3 are summarized. A full account of the interview findings falls outside of the scope of this paper and will be reported in a future manuscript. Next, the findings from the analysis of the data collected from the stage 4 co-design meetings are described as the 3C's (communication, consistency, connection) in telerehabilitation experience. The co-design solutions developed to address the 3C's prior, during and after therapy are presented.

3.1. Touch point identification through sharing stories of telerehabilitation experiences

Four touch points were inductively identified from the caregiver and clinician experiences with telerehabilitation that were shared during the interviews. The four touch points identified were: (1) child engagement in telerehabilitation; (2) perceived value of telerehabilitation services and caregiver engagement; (3) fit of using a telerehabilitation model and providing family with choice; (4) preparing the people and environment for telerehabilitation services. Each touch point served as a topic for the four co-design meetings.

3.2. The 3C's in telerehabilitation experience —communication, consistency, connection

Open coding of the transcripts and analysis of the arts-based outputs (e.g., drawings, chart paper, sticky notes) from the four co-design meetings led to the identification of three interconnected categories identified as impacting the telerehabilitation experience. These three categories are communication, consistency and connection (the 3C's). All invested parties (i.e., caregivers, clinicians, management) involved in the co-design meetings identified examples of how challenges with the 3C's impact experiences with telerehabilitation at KidsAbility. A desire to improve how the 3C's are experienced by caregivers and clinicians is apparent in the co-designed solutions and related prototypes. **Table 2** summarizes key information from analysis that describes the subcategories and categories related to the 3C's.

3.2.1. Communication

Caregivers, clinicians and managers recognized significant deficits in how the details of telerehabilitation as a service model were communicated. General information such as what is a telerehabilitation appointment (i.e., over video or phone), what occurs during a telerehabilitation appointment and what technology/set up is required for a telerehabilitation appointment was not adequately reviewed with caregivers prior to commencing with service. "Communication is the biggest key in all of this, it's lacking at some point or points. A new person coming in, jumping right to virtual…with no further communication, they're going to be lost." (Caregiver P1-2). A caregiver recalling her initial telerehabilitation appointment shared, "I remember my first session, and it was just chaos… (Caregiver P2-2). Without adequate communication prior to initial and subsequent telerehabilitation appointments, caregivers expressed feeling unprepared for the sessions, which impacted how meaningful the session was perceived to be, "If there was some sort of communication prior: this is what speech needs to see, this is what OT needs to see, let's do this activity because we can see both…. There was none of that, and it was overwhelming, and at the end of it, I was like, "Okay, cool, what

TABLE 2 Key components of the 3C's impacting experiences with telerehabilitation services.

	Categories		
	Communication	Consistency	Connection
Subcategories	About the telerehabilitation service model	In sessions between clinicians (e.g., format, quality)	Between treating clinician and family
	About the aims of the telerehabilitation session	In providing choice and flexibility in service	Should be established early on in service
	Should be multimodal and tailored to the family		Impacts buy-in and engagement in telerehabilitation services

did we accomplish?" (Caregiver P1-2). "If they had sent an email ahead of time that said, 'Hey, you can have snacks or something ready?' Then yep, I could have had it in place" (Caregiver P2-2).

Clinicians also identified the importance of communicating the aims of the session so that families could join feeling prepared, "having the family aware, if I want to see your kid in a walker, it can't be in storage, you have to have it ready for the session. So, preparing everyone beforehand, and then giving them the tools based on what we're hearing" (Clinician P7-4). Specific mention was made about the importance of ensuring clear and accessible communication about telerehabilitation services for families when English is not the primary language spoken. The need for "supporting parents for whom English is a second language…all the way through" (Parent Facilitator P3-3) including support for communicating with KidsAbility, accessing technology for telerehabilitation and teaching strategies for supporting caregivers to engage children in telerehabilitation appointments.

Communication impacted caregivers' expectations of therapy services. Caregivers identified feeling that there was a lack of communication provided to help inform them of what to expect with regards to wait times for visits and how many visits they could expect to receive, "I was on a waitlist for about a year, and I got one online session for an hour and that was it. I thought this was a long wait for nothing…My expectations were up to here. I got shafted." (Caregiver P3-4). A lack of clarity was also identified regarding the caregiver's role during a virtual appointment. Sharing one of her experiences with a telerehabilitation appointment, a caregiver stated, "I remember I did one therapy session, and they needed me to actually measure his spasticity. I was not prepared for this,…nobody told me that's what I'd be doing this virtual session." (Caregiver P4-1). All stakeholders identified the need for communication between the clinician and caregiver prior to commencing with a telerehabilitation session to help ensure all involved felt prepared and shared the same expectations for the appointment. "There's pre-work for the child and pre-work for the household and pre-work for the clinician. Are the 2 entities aligned in what's to be expected?" (Caregiver P4-1). The importance of matching therapy expectations is highlighted in these statements from clinician and manager participants, "Before you start a therapy, we [participant group] thought not only that the parents recognize the expectation that if this is a virtual service, you're going to need to do XYZ, but also, in return, that we're understanding what they're expecting from the service." (Clinician P1-3). "If everyone has the same expectation and is able to have done the work beforehand for that session, then you're going to be able to have a lot more success with the session rather than one person be disappointed." (Manager P2-1).

The mode of communication was also highlighted by caregivers as critical to consider when establishing effective communication between KidsAbility and families. When discussing modes of communicating one parent expressed, "My biggest point that I keep saying here is that emails get lost…Trying to go back for something that took place 3 months ago in emails, like where is that document? I know it's here somewhere. It's hard, right? So I wouldn't suggest an email touching base by any means. I think a phone call would be more efficient, ahead of time, before you got on to the link [for the telerehabilitation appointment]." (Caregiver P1-2). A clinician participant shared the following reflection about their experience sending emails to caregivers prior to telerehabilitation appointments, "…less and less parents are prepared because I think what's happening is there's just too much information. So, I think having that discussion versus an email would be helpful to really make sure we're on the same page about what this is going to look like." (Clinician P3-2). The importance of a "multimodal approach to communication" (Clinician P7-4), was recognized with an understanding that "some people may want to phone call, some people want to email,…asking how they best communicate… Adding a multimodal approach is what you'd need, considering how we can best deliver the information" (Clinician P7-4).

In addition to establishing a preferred mode of communication, tailoring the amount of information shared was also discussed as an important aspect of communication impacting experiences with telerehabilitation. A lack of communication prior to a telerehabilitation visit left caregivers feeling unprepared, while high volumes of information shared in follow up to an appointment was expressed to feel overwhelming. One mother shared this narrative about information that was provided after a telerehabilitation session: "My baby is medically fragile—that's one set of needs. And my eldest is on the spectrum [autism]. After one particular session, I was just inundated with information, and it was so overwhelming at the time because I had a baby and then a 2-year-old…But I was told, go watch this video, go on to this link, and then there were multiple attachments of 50-page documents of resources. I was so overwhelmed, but so desperate to have my husband and I help our 2-year-old" (Caregiver P5-4). Another caregiver said "I did get an email after my one call, with a whole bunch of resources…I thought this may be relevant and that, but it was so big that I just thought I would get back to that eventually, and I never did because it was overkill" (Caregiver P3-4).

3.2.2. Consistency

The importance of consistent practices and processes related to telerehabilitation services across clinicians and KidsAbility programs was identified by co-design meeting participants as another area instrumental in influencing experiences engaging with these services. Some caregivers had experience engaging in telerehabilitation services with multiple clinicians and reported that practices across clinicians varied. "So, I've done Zoom with 4 [different clinicians], and they are all completely different, and there is no consistency whatsoever in the way that they do it." (Caregiver P1-2). During a co-design meeting, a clinician shared the approach they took to support families in preparing for a virtual session, which according to caregiver participants, varied greatly from what they experienced with the clinicians they worked with, "It's just crazy that other people did it so differently, and it was so much more beneficial" (Caregiver P1-2). "I'm just going to say, from a parent's perspective, if there was that kind of training, it might help us on the consistency that we thought we would get" (Caregiver P2-2). Clinicians acknowledged inconsistencies in practice, "I don't even know what happens in other virtual sessions. I know what happened in my virtual sessions, but you're right. If there was some consistency…it would be more clear for everyone." (Clinician P4-2). Clinicians also recognized value in there being a "clear stepwise process, internally, for therapists, so that it's more consistent" (Clinician P4-2).

A desire for consistent choice and flexibility integrated into telerehabilitation service delivery was highlighted by caregivers and clinicians when discussing service experiences. A clinician described using a flexible approach to learn about how caregivers would choose to design telerehabilitation, "I had some success in the past with discussing with the parents and saying, 'How do you like to learn? How do you want this session to go?'… Do you like to learn the strategy on your own in a discussion format just with me and then the next week, your child can attend?" (Clinician P3-2). In contrast to the flexibility described by the clinician, a caregiver attributed their negative experience to a lack in choice regarding how telerehabilitation visits were conducted, "So, I do joint speech and occupational therapy at the same time… And I've tried very hard to get out of having to do my sessions together, to do them separately, which I've not been successful with. They keep doing it." (Caregiver P1-2). "There was also some discussion around when KidsAbility calls to make an appointment, whether the parent could decide at that time, 'I'd like this appointment to be virtual, or I think I can make it in person,' whether that level of flexibility could be provided, so that isn't a decision that we're making blanket from the beginning. But when the appointments are scheduled, we can sort of think through whether at that time it might be more appropriate to do a virtual or in person." (Parent Facilitator P3-3).

3.2.3. Connection

Developing a connection between the clinician and family early on in service engagement was identified by caregivers as being critical to their experience with telerehabilitation services. Caregivers described connection as feeling like their clinician knew about their child and family beyond the therapeutic context, that the clinician valued caregiver input and the clinician collaborated with the caregiver in a partnership. "There has to be some connection built with the families as a whole. The parents and the children. You can't, for your first time, go on virtual, which we did, and expect the kids to listen and to cooperate and be comfortable to move forward" (Caregiver P1-2). Prior to commencing therapy involving the child, caregivers identified opportunities for building rapport with the clinician through early communication in the form of conversations about topics like what they are hoping from therapy, preferences for how visits occur and goal setting. "There still needs to be that connection with your therapist, more from the get-go" (Caregiver P1-2). When discussing goals, a caregiver shared, "So I think the goal setting is really important. The clinician obviously has that background, they are the professional, and they know what the goals are, but as a parent, that might not be the goal that you have for your child. It's probably still on there, but it might be number 10 on your list, but number one for your daily life and for the success of your child and your family unit might be a different goal that you're [the clinician] hoping to gain." (Caregiver P5-4). The importance of following the family's lead in identifying priorities for therapy was also recognized by KidsAbility staff, "what do the parents want? What are you trying to get out of this? That's what we need to focus on" (Manager P2-4).

When caregivers feel that they are in a safe space with a strong connection to the therapist they were more confident in sharing information about their child (e.g., interests, likes, dislikes) and therapy preferences. It is important that clinicians invite this connection-building dialogue with caregivers as caregivers may fear repercussions for speaking negatively about their experiences with services. "I didn't want to rock the boat because I had waited for so long that I didn't want to lose that opportunity for her [child]" (Caregiver P2-2). A caregiver participant recognized that often the invitation to have these initial connection-building conversations are not consistently extended to families, "We don't ask the parents what's overwhelming about this for you? It's all overwhelming, but what feels possible?… sometimes we don't check in on what do you [caregiver] need… Because if the parents are checked out,…you're not getting the child" (Caregiver P4-1). By taking the time to connect with caregivers, clinicians can learn things about the child that may enhance engagement in therapy sessions. As an example a caregiver shared, "whenever my kid is excited, accomplished even a small task, sitting next to her, you just high-five. That may be something that parent and clinician can talk about…so that can keep them pumped and motivated to be engaged" (Caregiver P3-1).

The impact of connection on experience with telerehabilitation services was also recognized by clinician participants. "If we're asking questions, then hopefully, we're getting information. And then they're feeling that buy-in" (Clinician P8-4). "It sends the message that KidsAbility cares about your family, if they're wanting to know things that aren't necessarily to do with their specific therapy. It's about you and your family and your child" (Clinician P1-4). Clinicians felt that service would be improved by "making that a standard, so that everyone just does these things to build rapport with your families, and really tailoring their service to that individual, feeling them out and building a relationship" (Clinician P1-4).

3.3. Co-designed solutions for improving the 3C's to enhance experiences with telerehabilitation

Solutions were co-designed by participants to address the 3C's (1) before; (2) during; and (3) after the visit. The solutions and related prototypes developed during the co-design meetings targeted these three parts of the journey, with a heavy emphasis on what can be done to support families and clinicians before the visit takes place. "That first pre-work will determine the format, the style, the extra things to get your child's attention. So for me, you've got to start at the beginning of the journey" (Caregiver P4-1).

The co-designed solutions are presented according to where participants felt they fit into the telerehabilitation journey. The solutions target either modifying the process related to engaging in telerehabilitation services at KidsAbility or developing a tool/resource that facilitates information sharing/gathering.

3.3.1. Before the visit

Both process and tool/resource solutions were co-designed to promote consistent connection and communication between clinicians and caregivers when beginning telerehabilitation. To ensure there was a consistent opportunity for early communication and connection development, participants recommended implementing a process whereby clinicians book an initial appointment (likely by phone or video) with only the caregivers present. Caregivers expressed that this type of appointment would give them an opportunity to share information about their child as a person (e.g., likes, dislikes, motivators, interests, personality traits) and speak openly about their concerns and priorities for therapy. Clinicians saw additional value in the opportunity to connect with caregivers prior to commencing with telerehabilitation as it would give them a chance to have a conversation about the options for service models, learn about the caregiver's preference for services (examples identified by caregiver participants included: gender of clinician, ethnicity of clinician, appointment time/frequency/length), and make a service plan tailored to the family. In addition to occurring prior to commencing with therapy, participants recommended that this type of parent only appointment take place any time there is a change in treating clinician or when families are moving from in-person appointments to a telerehabilitation platform.

Participants prototyped tools/resources that included questions and discussion topics that clinicians could use during the pre-appointment conversation. Questions included: do you have access to the required technology and a reliable internet connection? Would you benefit from having an interpreter present? What are your goals for therapy? Here is what to do if we get disconnected from our visit. It was thought that a tool like this could act as a decision support when deciding what approach to take for therapy visits. Caregivers recommended consistent use of a "get to know my child" form to support the clinician in getting to know things like the child's likes/dislikes, which then can be integrated into therapy sessions to support engagement. "That [Get to Know my Child Form] would include things like your child's likes and dislikes, knowing what their dislikes are is equally as important as going through the long list of things they do like, their favorite toys, people in their life… So we're talking a lot about how to get your child engaged to be part of these [telerehabilitation session]" (Caregiver P4-1). Low fidelity prototypes of an online portal where parents and clinicians could directly message, share resources and update documents such as the "get to know my child" form was discussed as a possible platform to enhance communication between clinicians and families.

As another solution for enhancing early communication between the organization and families, participants prototyped the idea of video and text-based resources to share information with families about what they can expect when engaging in telerehabilitation appointments. Participants envisioned these resources being provided to families to support them in making informed decisions about what service model (i.e., in-person, virtual, combination) would feel like a fit for them. Videos would include footage of what a telerehabilitation session looks like, discuss technology requirements and environmental set up as well as review the caregiver's role during these sessions. "Video tutorials meaning tutorials explaining for families what a virtual appointment could look like based on the child's age, their situation, their environment, their goals… We thought this was important because we're looking at some families thinking "virtual" means my child has to sit at the computer and engage in a computer game, and that's not always what we mean when we say virtual services for a child" (Clinician P2-3). Recommendations were made that these resources should be easily translated into a variety of languages to enhance accessibility.

3.3.2. During the visit

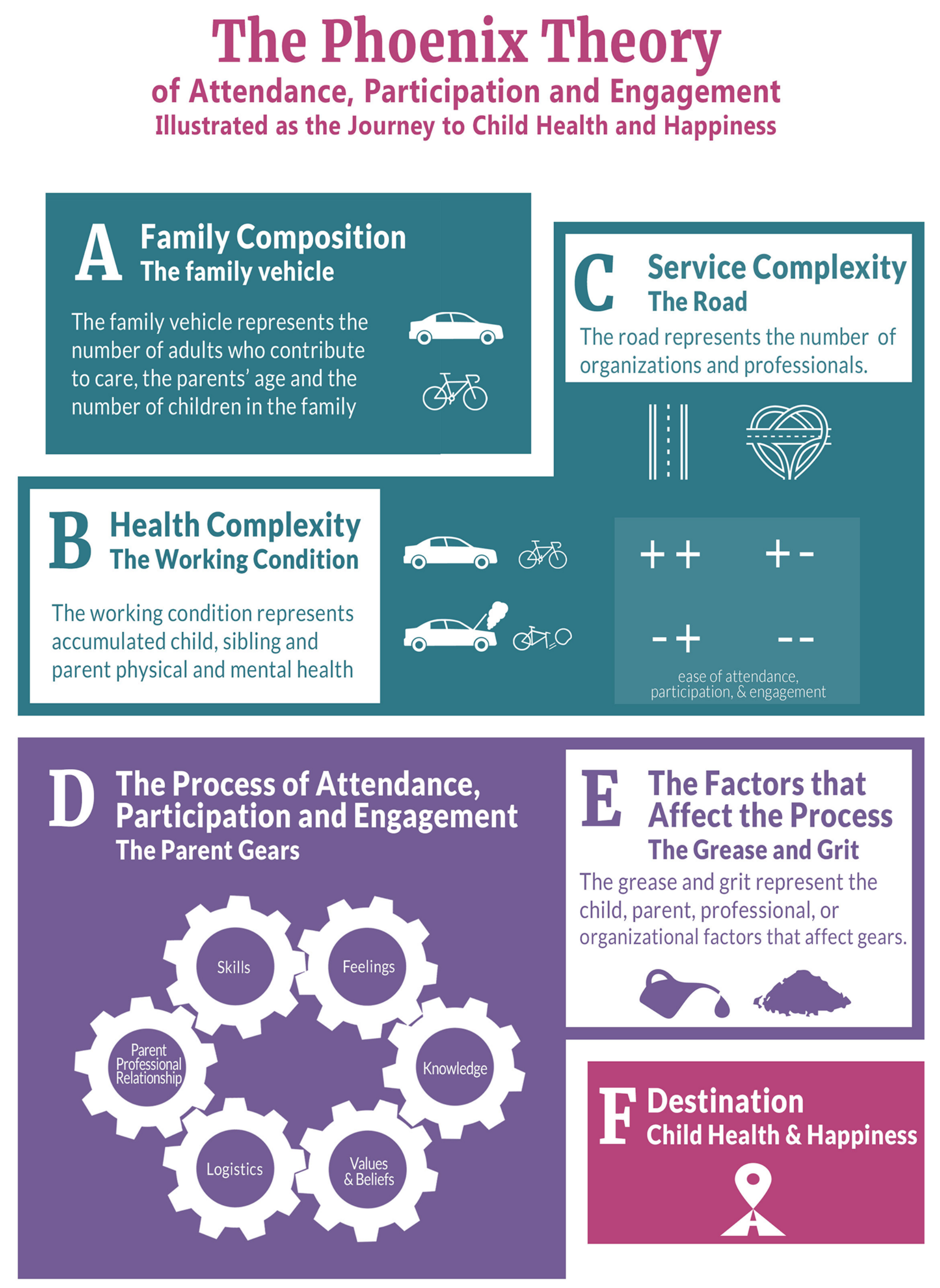
The primary codesigned solution for during the visit targeted the consistency in communication through a process where clinicians summarize key points from the session and develop a plan for the next session that aligns with families' priorities. The aim of this solution is to establish a process to ensure that families complete the session with strategies they felt comfortable trying at home and an understanding of what they needed to have set up to feel prepared for the next session. "It's the prep for the next visit if that makes sense. It's developing that action plan and that take-home" (Clinician P1-1). This process creates consistent opportunities for clear communication and shared expectations about upcoming appointments.

3.3.3. After the visit

Participants co-designed a process for follow-up after an appointment or block of sessions that facilitated authentic and individualized information sharing and communication methods. This solution was driven by caregivers' experiences of receiving emails in follow up to a visit with large amounts of content containing strategies and resources that felt generic. Participants recommended that in conversation with caregivers, clinicians inquire about preferred formats of receiving communication as well as the amount of information a caregiver prefers to receive. Caregivers made recommendations for "a more streamlined approach to the follow up. If it is resources and videos, ensuring that the parent has time to be able to view those and read over it. Having different ways of presenting material that isn't an email…" (Caregiver P5-4). A process to streamline how families engaged in telerehabilitation can access physical resources (e.g., loan of gait aids or positioning devices) from KidsAbility was also identified as a solution to enhance experience. Currently, families accessing services virtually need to come on site to pick up these physical materials, which one caregiver said, "defeated the purpose of online" (Caregiver P5-4).

4. Discussion

The aim of this project was to determine what solutions could be co-designed to enhance pediatric telerehabilitation experiences by understanding and incorporating the experiences of caregivers, clinicians and management. The 3C's emerged from the codesign process as key factors that influence engagement in telerehabilitation before, during and after a visit. The co-designed solutions were proposed to improve families access and engagement in telerehabilitation services. The Phoenix Theory of Attendance, Participation and Engagement (the Phoenix Theory) depicted in **Figure 1**, examined missed appointments in the context of in-person pediatric rehabilitation at KidsAbility and provided a theoretical foundation our work (15). The Phoenix Theory describes six interconnected gears that influence the process of parents attending, participating and engaging in therapy including: skills, feelings, knowledge, values and beliefs, logistics, and the parent-professional relationship (15). Additionally, the theory describes factors at the level of the child, parent, professional or organization that interact with the parent gears as either grit (inhibits gear movement) or grease (facilitates gear movement) (15). Although not developed or tested in the context of pediatric telerehabilitation, we see alignment between our findings and some



The family vehicle represents the number of adults who contribute to care, the parents' age and the number of children in the family

The road represents the number of organizations and professionals.

The working condition represents accumulated child, sibling and parent physical and mental health

The grease and grit represent the child, parent, professional, or organizational factors that affect gears.

FIGURE 1
The Phoenix theory of attendance, participation and engagement (15). © 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group. Reproduced with permission from Informa UK Limited through PLSclear.

the constructs of this theory. The trustworthiness of our findings, including the co-designed solutions, is enhanced through theoretical triangulation with components of the Phoenix Theory.

The connection between the clinician and the family was identified in our findings as a factor impacting experience with telerehabilitation. A desire to establish and maintain this connection is evident in the co-designed solutions developed (i.e., conversation with caregivers about their child). The element of connection discussed in our findings is akin to the parent-professional gear represented in the Pheonix Theory (15). According to the Phoenix Theory, a trust-based relationship and connection between clinician and caregiver enhances agreement between these two parties related to how to move forward in therapy (15). Relationships and collaborations have been recognized as indicators of levels of engagement in therapy (17). In a study exploring engagement and therapeutic alliance in pediatric telerehabilitation, rapport, connection and collaboration were identified as influencing caregiver engagement in telerehabilitation services (10). These findings are further supported by a qualitative systematic review exploring engagement in early intervention telerehabilitation, where building rapport between caregiver and clinician was linked to improved therapeutic outcomes, facilitating open communication and enhancing caregiver buy-in (21). This review highlighted the benefit of establishing early therapeutic rapport, suggesting relationship building should begin prior to telerehabilitation commencing (21), aligning with the co-designed solution recommending an appointment between clinician and caregiver prior to starting teletherapy with the child.

The Phoenix Theory identifies resources as one of the factors that can add grit or grease, influencing how the parent gears operate (15). Resources as described by the Phoenix Theory, include information and organizational supports, amongst other resource groupings (15). Co-designed solutions geared toward developing video tutorials and text-based resources about telerehabilitation services align closely with the Phoenix Theory's informational resources, which are factors that can influence engagement and experience with services. Examples of resources related to organizational supports are the possible adaptations and flexibility of service options (15). Our findings indicate the need for clinicians to consistently communicate service options available to families and a desire from caregivers to have a choice in their preferred service model. In a 2023 realist evaluation of telehealth in children with neurodisabilities, the importance of offering caregivers the choice to participate in telerehabilitation as part of a hybrid model (i.e., option for in person appointments, telerehabilitation appointments or both) was critical to their acceptance of telerehabilitation as a meaning option for service (40).

Communication and expectations were closely linked concepts in our findings and are represented individually as factors influencing the parent gears in the Phoenix Theory (15). Many of the co-designed solutions from our project aimed to establish consistency in the content and quality of the communication between the organization and families, with the hopes of aligning expectations for telerehabilitation service. The co-designed solutions targeted process change and resource development to achieve improvements in communication. The Phoenix Theory describes higher levels of parent engagement in services when there is alignment between what they expected the service to be like and what they received (15). Expectations are closely connected to the knowledge parent gear in the Phoenix Theory (15). In our findings, parents expressed not knowing what to expect with regards to telerehabilitation services, sharing that this knowledge was not adequate or consistently communicated and experiences with one clinician could be very different from service with a different clinician. Literature on caregiver expectations of therapy shows that caregivers enter into therapeutic interactions with expectations for their child, the clinician, the service organization and themselves (41). An ethnographic study exploring engagement in outpatient pediatric rehabilitation reported that engagement in therapy increases when expectations for therapy are aligned between caregiver and clinician, specifically when there are clear expectations about roles within the sessions (17).

Communication has been identified as one of the most important factors influencing parent engagement (15) and according to our findings is highly influential to the telerehabilitation experience. Collaborative, two-way communication, where caregivers feel listened to and feel their input is valued has been identified as critical to engagement in pediatric telerehabilitation services (10, 21, 40). With the recognition that it will take more of the clinicians' time, the use of multimodal communication approaches within and outside of telerehabilitation appointments has been identified as instrumental in facilitating engagement and connection (21). The need for using a multimodal approach to communication (e.g., using a combination of email and phone communication according to preference), tailored to each families' context is recognized in our findings and the co-designed solutions.

A limitation of this work is that the sample can only be described from a relatively small set of demographic questions focused on maximizing the diversity of the sample according to the KidsAbility context (e.g., KidsAbility site, clinical discipline, age of child receiving service, access to reliable internet connection). Additional demographic information such as income level or parent education level, was not collected and therefore potentially limits the transferability to other contexts. A strength of this work is that it included a broad range of perspectives including caregivers, clinicians, KidsAbility management and interdisciplinary researchers in all phases of the project. Due to time and resource constraint, there was not opportunity to review the co-designed solutions with participants who took part in the co-design groups, however they were validated with the steering committee members, some of which have lived and living experience with telerehabilitation services. We acknowledge that although the project is grounded in the field of pediatric rehabilitation, the child and youth voice is not represented in our work and should be incorporated into future research in this area. A possible avenue for gaining insight into youth experience with telerehabilitation is engaging with the established KidsAbility Youth Advisory Council for future projects. Although the project was completed with a single site potentially limiting the transferability of the findings, this allowed for a rich understanding of the study context and the development of solutions relevant to KidsAbility.

To date, our project has developed co-designed solutions aiming to enhance experiences with pediatric telerehabilitation. The relevance and validity of these solutions to practice has been explored through examining their relationships to theory and current evidence. Next steps of this project are to work alongside KidsAbility to implement and evaluate the impact of these solutions on organizational practices and user experience with telerehabilitation services in this setting. Evidence-based knowledge products developed to support pediatric telerehabilitation appointments, such as the Telerehabilitation Hub for Children with Disabilities and their Families (42) will be explored to operationalize the solutions developed from our co-design work in the KidsAbility context. Additionally, our team has plans for disseminating information about the co-designed solutions across an established pan-Canadian network of research and clinical pediatric rehabilitation organizations.

Data availability statement

The datasets presented in this article are not readily available. The data for this study cannot be shared to protect the privacy and confidentiality of participants. The dataset is unavailable to be requested.

Ethics statement

The studies involving humans were approved by Hamilton Integrated Research and Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MR: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Visualization, Writing – original draft. LL: Conceptualization, Funding acquisition, Methodology, Writing – review & editing. CL: Conceptualization, Formal analysis, Methodology, Writing – review & editing. JLL: Conceptualization, Data curation, Formal analysis, Funding acquisition, Methodology, Writing – review & editing. MNP: Formal analysis, Investigation, Methodology, Writing – review & editing. BD: Conceptualization, Funding acquisition, Methodology, Writing – review & editing. MP: Conceptualization, Formal analysis, Funding acquisition, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Transitions Pop-ups: Co-designing client-centred support for disabled youth transitioning to adult life

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Background: When transitioning to adulthood, youth with disabilities and their families face many service gaps. Successful inter-agency collaborations can promote family-centred, inclusive transition support amenable to personal choice and health conditions. This paper reports the 3-year co-design process of an innovative transition service that links a pediatric hospital and adult service agencies and addresses key areas of transition preparedness with joint accountability.

Methods: A team of pediatric rehabilitation professionals, adult service providers, young adults with disabilities and their families, and researchers engaged in a co-design process over three years. Following a design thinking (DT) framework, the team went through an iterative process of Empathize. Define, Ideation, Prototyping, and Testing phases. The trial-and-error process allowed for deeper reflection and an opportunity to pivot the design.

Results: The co-design yielded *Transitions Pop-ups*, a nimble service model that can “pop up” at critical times and places to meet clients’ urgent and emergent transition-related needs. Two pilot sessions were conducted at the testing phase with adult service agencies. The final model included five key elements: (1) community partnership; (2) targeted information sharing; (3) peer mentoring; (4) action (on-the-spot completion of a key transition task/activity such as submitting an adult funding application); and (5) warm handover.

Conclusion: The co-design process highlighted the importance of open communication and iterative prototype testing as a means for trialing new ideas and clarifying the intent of the project. The DT framework optimally facilitated the co-development of a contextually relevant and sustainable service model for pediatric rehabilitation clients and families.

KEYWORDS

Transitions Pop-ups, transition to adulthood, pediatric rehabilitation, design thinking, human-centred design

1 Introduction

Transition from childhood to adulthood is a dynamic and multidimensional process. Once passing the age of majority, young adults often face societal expectations to go through educational, vocational, and legal status changes, take on new roles and responsibilities, and forge new relationships. For youth with disabilities, the transition process involves additional tasks and considerations associated with the move from pediatric to adult-oriented healthcare and social services. In Canada, young people transition from pediatric to adult healthcare systems by the age of 19. In contrast to pediatric services in which one or two main organizations provide holistic and developmentally appropriate care, adult services tend to be more dispersed and are managed by a wide range of specialists including primary care, hospital-based services, and community organizations with little formal coordination among them (1). Adult service users (individuals with disabilities and their families and other supporters) are expected to navigate the complex system on their own as autonomous individuals with full decision-making capacity, which might not always reflect the interdependent nature of disabled youth and their families' lives (2).

The gaps in transition support for youth with disabilities and their families have been widely recognized. Some of the key obstacles identified in the literature include limited funding and services for adults with disabilities (3), the scarcity of coordinated, holistic, and life-course planning (4), and the lack of inter-sectoral care coordination that would facilitate a smooth transition (5). Suboptimal transition management may contribute to poor health outcomes including the risk of preventable complications and inappropriate reliance on emergency health services (6). Given the increasing number and diversities of youth with disabilities transitioning to adult services, researchers and service providers have also emphasized the importance of addressing a wide spectrum of life transitions (e.g., educational, vocational, and social participation opportunities) beyond clinical transfer (5).

In Canada, a national guideline for transition calls for the removal of barriers to inter-agency collaboration to promote family-centred, inclusive support amenable to personal choice and health conditions (2). A small but growing body of evidence suggests that a coordinated, "warm" handover to adult service providers can increase continuity of care and health service utilization (7, 8). Continuity of health service utilization reportedly reduced intensive re-engagement in the health system after reaching a point of crisis (8). The national guideline also emphasizes that design and delivery of transition services should involve multiple stakeholders including pediatric and adult care providers, policy makers, researchers, government agencies, and most importantly, youth with disabilities and their families.

Recently, the application of human-centred design (HCD) in healthcare settings has been growing exponentially with the call for client-centred care. HCD refers to a collaborative, people-centered, and interactive approach for designing products, services, or systems and is considered particularly effective when solving complex real-life challenges (9). A review by Göttgens and Oertelt-Prigione (10) identified 82 studies published between 2000 and 2020 that employed HCD approaches across various areas of health innovation. Among various HCD methods, design thinking (DT) emphasizes developing empathy for users and leverages end-user insights through an iterative process of empathize, define, ideate, prototype, and test. Through empathizing and defining, the designers first gain a deep understanding of what users really want and need to create an accurate problem statement. Ideation encourages the various possible ideas to choose from, not just looking for the best single solution. In prototyping and testing phases, the selected solutions are put to the users for them to test and provide feedback (11). DT was reportedly effective in having end users as design partners who engage in the entire design process, including feedback, idea generation, and decision-making (10).

To date, limited literature exists regarding the use of HCD in designing transition support services, with a particular scarcity of detailed description on the collaborative process in its entirety (12). Although design researchers have strived to create an inclusive co-design mechanism to meaningfully engage with end-users with diverse cognitive and physical abilities (13), the breadth and effectiveness of the HCD in designing transition services remains largely unknown. One notable exception is a study by Fortune et al. (14) that employed DT to co-design resources for young adults with cerebral palsy in transition to adult care. However, while this article provides rich descriptions of the initial phases of the co-design process, it ends at the prototyping stage without delineating whether and how prototypes were tested or implemented in actual service.

The goal of this paper is to describe the co-design process of *Transitions Pop-ups,* an innovative client-centred transition support service that links a pediatric hospital and local adult services to optimally support young adults and their families in transition to adulthood. We describe the process in which the *Transitions Pop-ups* model was co-designed by pediatric rehabilitation professionals, adult service providers, youth with disabilities and their families through an interactive and iterative design cycle over three years. In response to the call for transparency in reporting the co-design process (12), we report guiding principles underlying this inter-agency service model, facilitators and barriers encountered in the co-design process, and lessons learned. This knowledge can contribute to the growing body of HCD methods in healthcare practice and strengthen the evidence base for client-centred transition support in pediatric rehabilitation.

2 Project background

The project was conducted at Holland Bloorview Kids Rehabilitation Hospital (HBKRH) in Toronto, Canada, as part of the hospital's Transitions Strategy, a multi-year initiative to support a meaningful transition to adult life for clients graduating from the pediatric services. The Transitions Strategy aimed to enhance existing services and design new evidence-informed programs in partnership with young clients, families, and adult services (15). The objective of the co-design initiative was to create a scalable and sustainable service model to support collaboration between pediatric and adult services. To maximize involvement of hospital clients and families as "design partners" (10), the DT method was used to guide the entire process. One final prototype generated from the prototyping stage went through the testing phase to assess its feasibility in real-life situations. The service model was named *Transitions Pop-ups* and has been implemented as part of regular service at the HBKRH since 2019.

3 The design team

The overall project was led by a team of two occupational therapists with a combined 15 years experience in pediatric rehabilitation, system navigation, research, and solution-focused practice (LT&LB) and the Transitions Strategy Director (CC). Two researchers (YS and AO) conducted a program evaluation of the activities, discussions, and decisions. Other contributing team members included youth facilitators,[1] family leaders,[2] pediatric hospital clinicians (nurse practitioners, nurses, occupational therapists, therapeutic recreation specialists, social workers), and service providers from local adult services. These team members played essential roles throughout the co-design process, including co-facilitation of the empathize & define and ideation phases, acting in the prototyping phase (live scale modeling), and testing the service delivery model. Representatives from the Rotman School of Management (University of Toronto) NeXus Team supported the empathize & define phase. Consultants from Ontario's Ministry of Health and Long-term Care Business Innovation Office (MOHBIO) provided expertise in HCD and project management support at the ideation and prototyping phases. Overall, there were more than 100 individuals involved in the co-design process.

4 Design process

In what follows, we describe the four phases of the co-design process (Figure 1). Data for this article were retrieved from multiple sources including strategic planning documents, meeting minutes, post-session participant feedback forms, session fieldnotes, and staff debrief documents collected over three years.

4.1 Empathize & define phase

The first phase of DT involves building empathy with end users and gaining in-depth understanding of their needs and priorities (10). While the conventional DT framework separates "empathy" and "define" phases, we deliberately merged them into one. This approach allowed us to empathically engage with clients and families, collaborating to define problems and opportunities. In 2017, our team conducted a series of in-person interviews and focus group sessions to collaboratively explore the pre- and post-pediatric experiences of clients and families. For this stage, the third and fourth authors (both Occupational Therapists) recruited youth with disabilities and their families as part of the Transitions Strategy's outreach plan. Recruitment methods included advertisements through the hospital's Family Resource Centre and word-of-mouth referral. Identifying key service providers in the community involved an environmental scan and leveraging the authors' professional networks.

Participants had the option to be interviewed either over the phone or in person. During in-person interviews, participants could choose to speak, write and/or have their answers transcribed in real time by the interviewer. In total, 89 participants took part, consisting of 30 former and current clients and/or their families from HBKRH, 27 HBKRH staff members, and 32 providers of local adult services. The young clients who participated in the project spanned ages 15–29, including both transition-aged clients (meeting the hospital's criteria of 15–21 years old) and those who had already undergone the transition process and wished to reflect on this period. Our participant selection purposefully represented the broad spectrum of HBKRH's disability and lived experience demographics, encompassing various physical, developmental, and/or neurological disabilities, as well as different educational, vocational, and social needs and aspirations for adult life.

Themes emerged from the interviews and focus groups, highlighting frustration with service gaps and a desire for a seamless, coordinated transition. Participants also noted the importance of developing self-management capacities among clients and families as a crucial factor for a smooth transition. The facilitators synthesized these themes into four key drivers for a meaningful transition: (1) helping clients to integrate into the adult system at a younger age; (2) starting transition preparation early; (3) strengthening community and peer support networks; and (4) increasing access to educational resources for clients, pediatric service providers, and adult service providers.

4.2 Ideation phase

Following the Empathize & Define phase, the team conducted two ideation sessions. In the DT framework, ideation is the process of generating, developing, and quickly testing as many ideas as possible (10). In the first ideation session, key stakeholders reviewed the aforementioned four key drivers for successful transition and discussed multiple ideas for a new service delivery model. In the second session participants further explored the ideas and created a series of small-scale prototypes. Two team members (LT and LB) led these sessions. In both ideation sessions, accommodated communication was offered to participants according to their developmental levels and communication preferences, including the use of Augmented and Alternative Communication (AAC) devices. Interpreters were available if needed for different languages, including American Sign Language.

4.2.1 Ideation session 1

The first ideation session took place in January 2018 convening eight HBKRH clients, eight family members, 19 HBKRH staff

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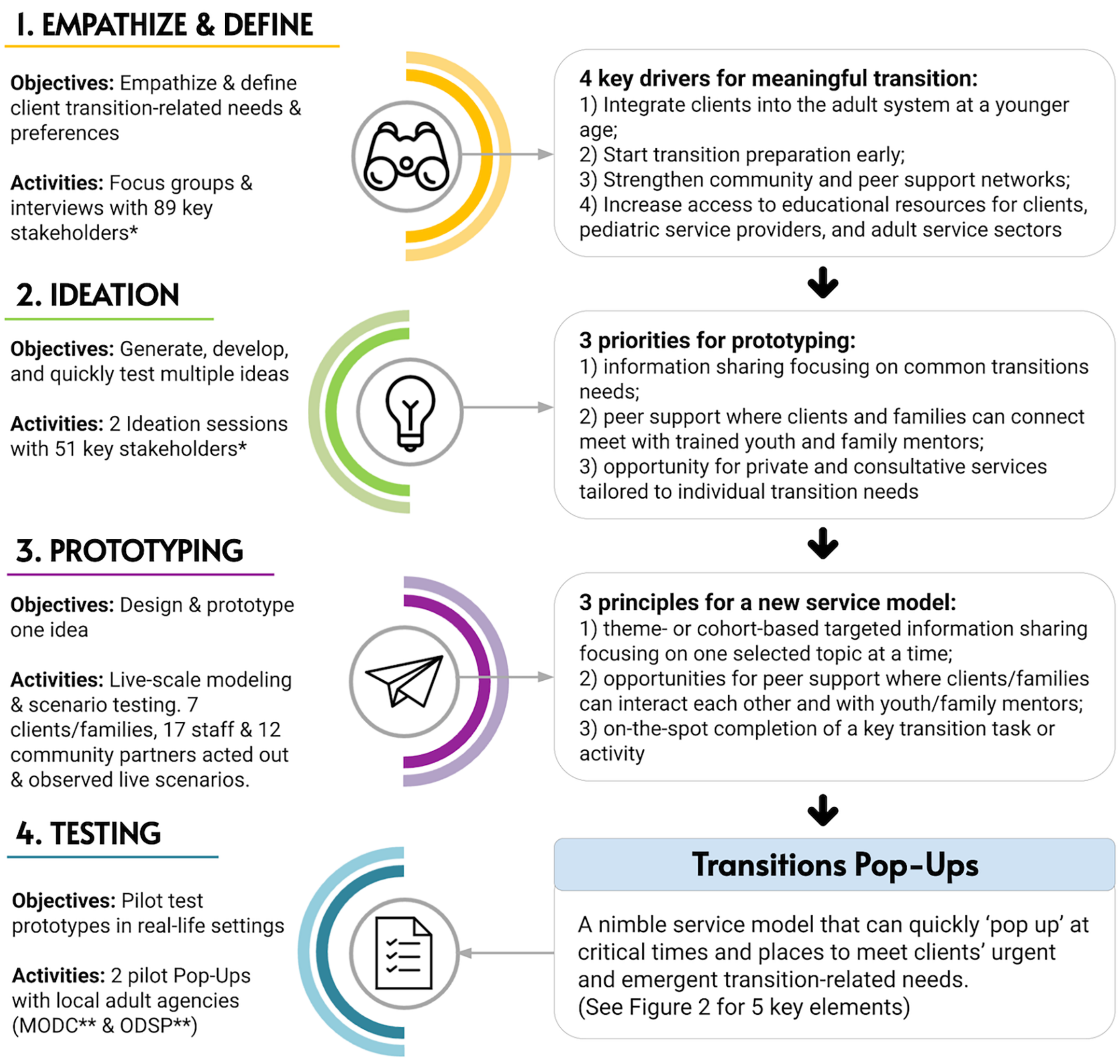
[1] Youth Facilitators (YFs) are peer service providers with childhood-onset disabilities with capacity to meet with clients individually, access patient health records, conduct clinical documentation, and make clinical referrals as needed. Since 2006, the role has been integrated in clinical teams at the HBKRH. For a detailed explanation of the youth facilitator role see Seko et al. (16).

[2] Family leaders are family members or caregivers with lived experience of supporting children/youth with disabilities who volunteer at the hospital.



1. EMPATHIZE & DEFINE

Objectives: Empathize & define client transition-related needs & preferences

Activities: Focus groups & interviews with 89 key stakeholders*

4 key drivers for meaningful transition:
1) Integrate clients into the adult system at a younger age;
2) Start transition preparation early;
3) Strengthen community and peer support networks;
4) Increase access to educational resources for clients, pediatric service providers, and adult service sectors

2. IDEATION

Objectives: Generate, develop, and quickly test multiple ideas

Activities: 2 Ideation sessions with 51 key stakeholders*

3 priorities for prototyping:
1) information sharing focusing on common transitions needs;
2) peer support where clients and families can connect meet with trained youth and family mentors;
3) opportunity for private and consultative services tailored to individual transition needs

3. PROTOTYPING

Objectives: Design & prototype one idea

Activities: Live-scale modeling & scenario testing. 7 clients/families, 17 staff & 12 community partners acted out & observed live scenarios.

3 principles for a new service model:
1) theme- or cohort-based targeted information sharing focusing on one selected topic at a time;
2) opportunities for peer support where clients/families can interact each other and with youth/family mentors;
3) on-the-spot completion of a key transition task or activity

4. TESTING

Objectives: Pilot test prototypes in real-life settings

Activities: 2 pilot Pop-Ups with local adult agencies (MODC** & ODSP**)

Transitions Pop-Ups

A nimble service model that can quickly 'pop up' at critical times and places to meet clients' urgent and emergent transition-related needs.
(See Figure 2 for 5 key elements)

FIGURE 1
Human-centered design phases and activities in the *Transitions Pop-ups* design process. *Stakeholders including clients/families, hospital staff & community partners; **MODC, March of Dimes Canada; ODSP, Ontario Disability Support Program.

(comprising service providers and leadership), and 16 collaborators from local adult services. Initially, participants reviewed the four key drivers that emerged from the Empathize & Define phase. Subsequently, they delved into the "pain points" experienced by clients and families, which encompassed feelings of being overwhelmed when introduced to adult services, a sense of disconnect from peers undergoing similar experiences, and a desire for opportunities to develop essential life skills before transitioning from pediatric services.

Participants were divided into six groups of 7–8 members and one facilitator. Participants were encouraged to think about how partnerships with the adult sector could help pediatric clients and families better prepare for transition, write down as many ideas as possible on sticky notes, and share their notes with other group members. Following the small group discussion, a larger group discussion ensued, allowing for the exchange of diverse stakeholder perspectives and feedback on individual ideas. Following the session, the facilitators collated and summarized the findings to present back to the group during the subsequent ideation session.

4.2.2 Ideation session 2

The second ideation session occurred in April 2018 with 51 stakeholders consisting of 16 HBKRH clients and their family members, 19 HBKRH staff, and 16 collaborators from local adult services. While most participants from the first ideation session were able to attend the second session, a few opted out due to scheduling conflicts and other commitments. Consequently, there was a significant overlap of representatives from the initial session along with the inclusion of new participants.

During this session, participants were divided into six groups of 7–9 people, tasked with swiftly devising a small-scale prototype for a service/program aimed at addressing themes identified in the ideation session 1. Participants were encouraged to suspend judgment and expand on wild, out of the box ideas by drawing, in words, through songs and acting, arts and craft materials, and costumes. A member of the design team facilitated discussions within each small group.

Each group underwent two rounds of rapid prototyping and shared their ideas with the larger group. Emphasizing empathy towards service users and providers, participants were encouraged to consider their own feelings during the experience and ways to foster connections between the pediatric and adult systems. One lead facilitator guided a discussion among the larger group, while the other documented participants' feedback, insights, and feelings about each prototype.

4.3 Prototyping phase: live scale modeling and scenario testing

Following the two ideation sessions, two team members (LT & LB) synthesized participant feedback and fieldnotes, revisiting four key transition drivers from the Empathize & Define phase. The team distilled this information into three guiding principles for prototyping a large-scale transition service: (1) information sharing focusing on common transition needs; (2) peer support where clients and families can connect with trained youth and family mentors; and (3) opportunity for consultative services tailored to individual transition needs. This led to the creation of a prototype: a mobile transitions service adaptable to various locations across the city.

In August 2018, seventeen hospital staff, twelve adult care professionals, and seven client and family members participated in live-scale prototyping. The set-up mirrored a "mobile fair," consisting of multiple booths representing adult agencies specialized in areas such as independent living, attendant care, life skills, legal needs, and income support (target need: *information sharing*). A registration area with two transition facilitators was set up to help visitors navigate through the booths (target need: *consultative services*). There was also a private booth where visitors could access their health records on the spot and a lounge area for networking with youth/family mentors (target need: *peer support*).

Two simulated scenarios tested the live-scale prototype involving two youth-parent dyads ("simulators"). One dyad included a youth facilitator and hospital manager acting as a transition-aged youth and parent, and the other included a 15-year-old hospital client and her mother. The first scenario entailed a 17-year-old youth attending the mobile fair with her mother. The youth's goals included going to college, making friends, and living on her own after high school. In the second scenario, the 15-year-old youth and her mother were looking for information about community day programs available after high school and seeking support for navigating new routines and emotions that will arise during this major life change.

In each scenario, the simulators first met transition facilitators at the registration desk and engaged in a discussion about their hopes for adulthood. The facilitators then assisted the simulators with browsing related information, connecting with relevant adult services, and completing key transition tasks such as filling out adult funding applications. During the prototyping, a panel of stakeholders observed and provided on-the-spot feedback to the simulators, and the simulators improvisationally implemented the feedback. At the end of each scenario, the simulators were interviewed about their experiences and how the service could be more meaningful for clients and families. All participants (i.e., simulators, service providers at the booths, youth/family mentors who played transitions facilitators, and observers) were invited to complete a feedback survey about their experiences and share what was most effective about the prototype, potential challenges, and possible solutions.

Most participant feedback indicated that the live-scale prototyping was a one-of-a-kind opportunity to connect pediatric and adult service providers and co-design a service through authentic scenarios and role play. They valued several aspects (e.g., on-the-spot access to client health records to help simulators complete adult funding applications in real time). However, many participants felt the prototype was overwhelming for the families who received piles of pamphlets without knowing where to start and did not have time to connect with all adult providers of interest. Observers also suggested more innovation, seeking to avoid replicating existing information sessions offered at high schools (e.g., job fairs) or through HBKRH.

Following the live-scale prototyping, the team reviewed session feedback, noting the prototype's overwhelming nature despite the shared desire among participants for a "one-stop-shop". Exploring where the mismatch of desire and prototype arose, the team revisited the lessons from the first two phases and revised the guiding principles. This process generated three refined principles that would characterize the new service delivery model: (1) targeted information sharing focusing on one selected topic at a time; (2) opportunities for meaningful peer support; and (3) on-the-spot completion of a key transition task/activity.

After several refinements, the team devised a new service model: *Transitions Pop-ups*. This nimble and agile service can "pop up" at critical times and locations to meet clients' urgent and emergent transition needs. Just like pop-up retailing, the new model aimed to engage clients dynamically and generate a feeling of relevance and interactivity while maximizing resources. The new model targeted specific transition needs, highlighting the importance of authentic partnership with adult services for successful task completion.

4.4 Testing phase: two pilots with adult sector partners

Following the prototyping, the team conducted two pilot *Transitions Pop-ups* sessions to test the model in Spring and Fall 2019.

4.4.1 Pilot 1: Try out an adult community program

The first pilot was conducted in partnership with the March of Dimes Canada's (MODC) Learning Independence for Future Empowerment (L.I.F.E) program. The L.I.F.E program supports young adults with disabilities (aged 15–30) in developing essential life and independence skills. The purpose of the event was for pediatric clients to try out a community program for adults and connect with adult service users. The program was a natural partner to test the *Transitions Pop-ups* model, as the MODC manager was a collaborator in the co-design process from the onset of the project.

The pilot took place over two sessions, with the first session taking place at HBKRH, and the second session being hosted at MODC. Eight clients and ten family members took part in the first session. The session focused on exploring participants' preferred futures after high school and creating a vision of what a meaningful adult life might look like (e.g., activities, interests, roles). MODC staff shared a presentation on the L.I.F.E program and explained how the program can support clients in fulfilling their needs (principle 1: *targeted information sharing*). In the second session, three HBKRH clients and six family members joined the L.I.F.E program for a day. Clients participated in an independence-building activity with actual L.I.F.E. program participants (principle 3: *on-the-spot completion of a key transition task/activity*). Clients' family members had opportunities to mingle with other family members and a family peer mentor in a separate room (principle 2: *meaningful peer support*). In the post-session feedback, participants reportedly found it helpful to meet with young adults and families who had experienced the transition to adult life, and to try out an adult community program before graduating high school.

4.4.2 Pilot 2: connect with the primary adult funding agency

The second Transitions Pop-up was piloted in Fall 2019 with the Ontario Disability Support Program (ODSP). In Ontario, Canada, ODSP is the provincial funding program providing income and employment support for adults with disabilities based on medical and financial need. Although applying for ODSP marks a significant transition-related task for many clients and families, completing the lengthy funding application is often overwhelming during a time of complex life transition (1). Conversations with ODSP staff also revealed the desire for more opportunities to meaningfully interact with their clients upon funding application.

The pilot session took place at an ODSP office in Toronto with five HBKRH clients and eight family members. The goals of the event were for clients and families to increase their understanding of ODSP, complete an ODSP application form (if eligible), and learn the next steps in the ODSP application process and what to expect in the future. At the beginning of the session, a family leader shared her lived experience with applying for and receiving ODSP and what had been helpful (principle 2: *meaningful peer support*). Next, ODSP staff presented on the ODSP program, eligibility, and application timeline (principle 1: *targeted information sharing*). The session was purposefully designed to be interactive, with ODSP staff providing opportunities for individual consultation. At the end of the session, all eligible clients and families had completed an ODSP application with 1:1 support from ODSP caseworkers and HBKRH staff (principle 3: *on-the-spot completion of a key transition task/activity*). In the post-session feedback form, ODSP staff reported an increased awareness of clients' and families' needs and real-life challenges facing them with respect to ODSP applications.

The two pilot sessions at the testing phase were well received by participants. Following the two pilots, two additional elements were incorporated into the *Transitions Pop-ups* model to reflect client, family, and staff feedback. The five core elements of the model are shown in Figure 2.

5 Discussion

Over a three-year interactive co-design process, *Transitions Pop-ups* emerged as an innovative service model that can be tailored to diverse client needs, goals, and preferences. The model encourages proactive referrals, letting young clients explore adult programs before transitioning to adulthood. Since 2019, *Transitions Pop-ups* have expanded to 20 unique sessions that cover various topics including financial and legal support, health and wellness, life after high school, and personal care. All these topics originated from the co-design process and developed into individual sessions to cater optimally to participants' needs. Many of these sessions have been conducted in partnership with local adult services, including both the MODC and ODSP. In 2021, the model was recognized as a leading practice by Accreditation Canada. As of 2023, HBKRH offers greater than 70 *Transitions Pop-ups* per year, on 20 discrete transition topics, with 1092 client/family attendances since 2019.

The Design Thinking (DT) methodology guided the entire process by actively involving multiple stakeholders, generating new ideas, and developing a service delivery model that can be implemented in regular service at HBKRH. Although we described the process sequentially, it felt fluid and messy, involving constant iterations and refinement of ideas. DT's fundamental tolerance for trial and error was invaluable to the co-design process. As previously mentioned, the initial live-scale prototype felt overwhelming for participants, despite it being developed through multiple iterations and dialogues. However, this "failure" highlighted the need to explore one transition-related task/activity at a time, rather than putting together vast information in a single physical space. The lesson learned emphasized the importance of embracing flexibility and remaining open to new ideas, rather than strictly adhering to one idea.

A key driver of success was positive and accountable partnerships forged between the pediatric hospital and local adult services. The design team established collegial relationships with local adult services, sharing a passion to facilitate seamless transitions. Early involvement of senior leadership significantly boosted the project's momentum, while donor funding supported the entire process. Most importantly,

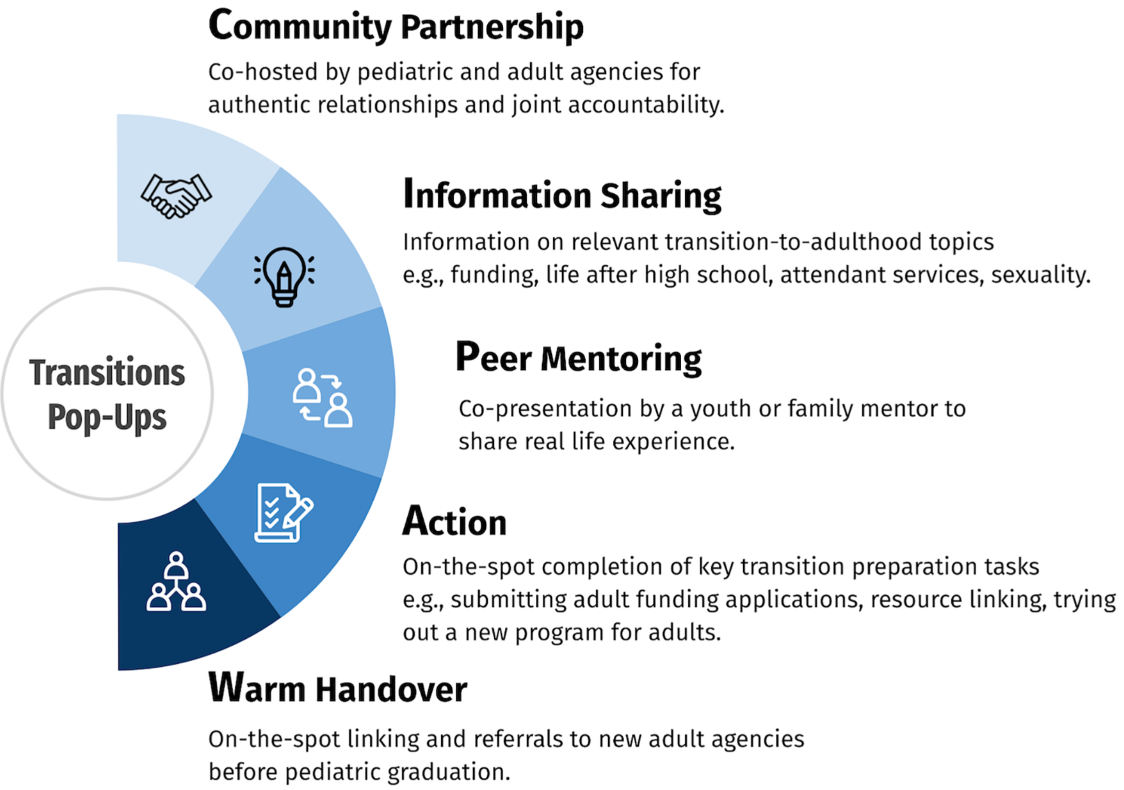


FIGURE 2
Five key elements of the final *Transitions Pop-ups* model.

the constant involvement of stakeholders who had lived experience of disability, such as youth facilitators, family leaders, former and current clients and families, was pivotal in steering the co-design process towards success. It was vital to implement inclusive and adaptive communication methods to ensure diverse voices were expressed and heard, thereby expanding the project's reach and relevance within the community.

In terms of barriers, the co-design proved to be time- and labor-intensive. To optimize time, the core members synthesized and shared ideas between the sessions, yet maintaining transparency in the decision making process was not easy. Existing literature lacks guidance on maintaining transparency in large HCD processes like ours. To address this gap, our project incorporated ongoing program evaluation and meticulously documented each activity, discussion, and decision to maintain an extensive audit trail. This allowed the team to provide ongoing feedback to improve the co-design process and the service model. Lastly, addressing the heterogeneous experiences of transitions to adulthood posed challenges. While we focused on common transition-related tasks and experiences applicable to many of our clients/families (e.g., life skills programs for adults, ODSP funding applications, legal considerations, sexuality), it may not encompass unique individual experiences of youth with disabilities and their families. Rehabilitation practitioners who wish to integrate DT in their service design should aim for adaptability, recognizing the diversity within the experiences of those they serve. We suggest embracing a dual approach—attending to general needs while remaining receptive to the nuances of specific circumstances. This flexibility allows for a more inclusive and responsive service design, ensuring that the broader aspects cater to many while leaving room to address distinct needs.

6 Conclusion

Our co-design initiative has both design and intervention implications. From a design perspective, the DT provided a useful framework to engage service users and providers, and the process of iteration and open feedback was vital to optimize service design and delivery. We learned that assumptions of shared understanding can sometimes be misleading; the live-scale modeling prototype met all requested needs of the group, and yet it was not embraced by collaborators. This trial-and-error process allowed for a deeper reflection and an opportunity to pivot the design. From an intervention perspective, the *Transitions Pop-ups* model has been built through consultation with best available evidence, community collaboration, and lived experience, and can be implemented across transition-related services and programs. Future initiatives in pediatric rehabilitation can use DT as a means for trialing new ideas and clarifying the core intent of projects.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

YS: Writing – original draft, Writing – review & editing. AO: Writing – original draft, Writing – review & editing. LT: Project administration, Writing – review & editing. LB: Project administration, Writing – review & editing. CC: Funding acquisition, Project administration, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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A case study of using community-based consensus methods to facilitate shared decision-making among a spinal cord injury network

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Spinal cord injury (SCI) research and policy decisions are rarely made in partnership with people with SCI, making them less relevant, applicable, and used by those whom the decisions are intended to support. Across disciplines, consensus methods have been promoted as a viable solution for supporting shared research and policy-based decision-making. In this paper, we describe a partnered approach between academic researchers and the Ontario SCI Alliance, a non-profit, SCI community mobilization network to co-develop and co-disseminate a community-based consensus exercise. The community-based consensus exercise included two modified Delphi surveys and one in-person retreat. The partnership's goal with this exercise was to facilitate shared decision-making for the development of their upcoming strategic plan. We then interviewed partners and participants from the Delphi and in-person retreat to discuss successes, challenges, and lessons learned from the exercise. Survey 1 was disseminated to over 2,500 members of the Ontario SCI community and received 374 responses (276 coming from people with SCI). Survey 2 had 118 responses, with 87 coming from people with SCI. The retreat had 73 attendees, including people with SCI, family/friends of people with SCI, clinicians, researchers, and SCI community and research organization staff/volunteers. The retreat included a presentation of the survey results, a clinician/researcher panel, and externally-facilitated working groups. All survey responses and retreat materials were synthesized. Using the synthesized feedback, the Ontario SCI Alliance was able to implement several changes for the Ontario SCI community, including higher-quality primary care experiences (reduced wait times, more accessible examining rooms), the development of a wound care strategy with the Ontario government, and an advocacy campaign for public coverage for catheters and urinary care supplies. From the five interviews conducted, five themes were co-constructed regarding the successes, challenges, and lessons learned from the exercise: (1) Inclusion, Diversity, Equity, and Accessibility; (2) Partnership; (3) Design Considerations; (4) Transparency and Clarity in Communication; and (5) Sustainability. Findings from this community case study demonstrate the feasibility of conducting a community-level consensus exercise among an equity-deserving group while providing detailed guidance for how to ensure future research and policy-based decision-making is shared across diverse knowledge users.

KEYWORDS

spinal cord injury (SCI), consensus methods, shared decision-making, research partnership, Delphi methodology, inclusive research, integrated knowledge translation (IKT), policy-making

Introduction

Paralysis is often viewed as the primary damaging outcome of a spinal cord injury (SCI). However, people with SCI experience complex physical and psychological complications (e.g., loss of bowel and bladder function, decreased skin integrity, and reduced feelings of independence) that someone without a SCI cannot understand (1). Beyond these complications, people with SCI have been marginalized and experience inequities (2, 3). People with SCI are seldom in positions to influence research, practice, and policy decisions, even when the decisions directly impact them. Indeed, researchers and policymakers have begun approaching people with SCI to be involved in research and policy initiatives. However, while engaging, some researchers and policymakers have been faulted of tokenism, which occurs when equity-deserving groups have limited decision-making power, promoting a false sense of representation and endorsement (4, 5).

Strategies for meaningfully incorporating multiple and diverse perspectives of SCI lived experience must be prioritized to combat tokenism and promote equitable decision-making. Across disciplines, consensus methods including the Delphi method (6), Nominal Group Technique (7), and Deliberative Dialogue (8) have been used to consider multiple perspectives in decision-making. As such, consensus methods may be valuable in improving decision-making with SCI communities.

Researchers have promoted consensus methods as promising for developing relevant and impactful research agendas (9, 10), while also advocating for equity-deserving groups to be involved in determining policies. Using consensus methods in a policy context can promote inclusion by ensuring decisions are informed by individuals directly impacted by the decisions (11, 12). When policy decisions are made *with*, and not *for* equity-deserving groups, there can be more confidence in the effectiveness and potential impacts of the policy. A critical step in advocating for more equitable policy-based decision-making is demonstrating the feasibility and impact of using consensus methods to address this issue. For SCI communities particularly, the Delphi method may be valuable given its previous use in policy contexts (13, 14) and unique features that promote inclusion.

Traditionally, Delphi methodology has been understood as a formal and systematic way for "experts" in a topic to arrive at consensus that involves the iteration and distribution of surveys in rounds until consensus is reached (6, 15). Delphi methodology has distinct features that can help address issues that SCI communities may face when convening to make decisions. Being able to complete surveys on your own time and privately, can help people who may lack time due to self-care or unforeseen health issues, face geographical or accessibility barriers, or feel intimidated by contradictory opinions and power dynamics (6, 15). Its use has extended to SCI peer mentorship research (ranging from 45 to 84 participants with SCI-lived experience) and in-patient rehabilitation best practices (one participant with SCI-lived experience) (16–18). While these Delphi studies have expanded the meaning of "expert" to extend beyond academic and clinical experts, to our knowledge, the use of a Delphi to facilitate community member engagement in SCI policy-making at the provincial level has yet to be explored.

Given its quantitative nature, the Delphi is one of the most commonly used consensus methods across disciplines (10). Yet, many published Delphi methods include limited reporting of the informal and internal processes to develop and carry out a Delphi, making it challenging for researchers and communities alike to learn about and subsequently use consensus methods in their work (10). To promote reporting transparency and explore the application of the Delphi method to communities, this paper presents a case study of using a community-based Delphi consensus method to support the Ontario SCI Alliance, a SCI mobilization network, in determining research and policy initiatives to fund in their organizational strategic plan. This paper aims to demonstrate the feasibility and impact of a community-based consensus method by describing:

1. The development and dissemination of the method.
2. The successes, challenges, and lessons learned from the perspectives of individuals involved in developing, disseminating, and/or participating in the method.

Context

The Ontario SCI Alliance (Alliance) was developed under the leadership of Spinal Cord Injury Ontario (SCIO) and the Ontario Neurotrauma Foundation. The Alliance has over 250 members, including over 70 organizations, and a readership of over 10,000 Ontario SCI community members. Throughout 2017, the Alliance hosted Summit meetings to bring together researchers, clinicians, policymakers, and people with SCI to address SCI clinical care, research, and policy issues. Twelve meetings took place, each focused on one of the following domains: bladder management, neuropathic pain, pressure injuries, primary care/community supports, acute interventions, wheeled mobility, self-management, cardiovascular integrity, emotional well-being, walking, upper limb integrity, and sexual health. For each domain, the Alliance worked with expert researcher clinicians to synthesize meeting proceedings with pre-existing evidence. After reviewing the syntheses, the Alliance deemed four key topics urgent to address: primary care/community supports, neuropathic pain, bladder management, and pressure injuries. The Alliance then revisited proceeding syntheses for the four selected domains (19–22) and determined 34 strategies for consideration in their upcoming 3-year strategic plan. If included, strategies would have effort, time and resources dedicated to their implementation.

The Alliance expressed the need to meaningfully include their membership when deciding on strategies to implement. The Alliance's Executive Director (PA) contacted a previous academic research partner (HG) to help achieve this goal. PA and HG had previously partnered on a series of research projects on disseminating SCI Physical Activity Guidelines across Ontario (23–27). HG applied for funding to support a trainee (EG) to co-lead the new partnership's activities, and invited SS to build and think through the study's methodological components. Through discussions within the partnership, it was determined that co-developing a large-scale, community-based consensus method informed by Delphi methodology could help the Alliance meet its goal.

Development and dissemination of the community-based consensus method

The community-based consensus method included one initial survey (Survey 1), one subsequent survey (Survey 2) and a one-day in-person retreat. Both surveys were hosted on SimpleSurvey^{TM} Software, and the retreat occurred at the Hart House in Toronto, Canada. Figure 1 outlines each stage and associated timelines.

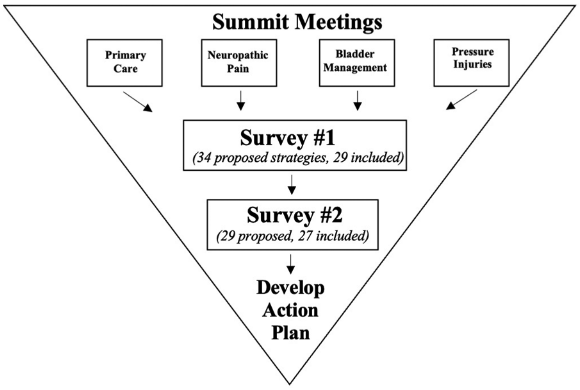

FIGURE 1
Visual representation of community-based consensus exercise.

The partnership adopted an integrated knowledge translation approach, meaning that all partners (three researchers, one community partner with SCI lived experience and decision-making power with the Ontario SCI Alliance) were meaningfully engaged throughout the research process. Supplementary File S1 includes a detailed account of the partnership's development and activities.

Survey 1 development

To create survey content, the 34 pre-determined strategies were organized by domain: primary care and community supports *(n = 10 items)*; neuropathic pain *(n = 8)*; bladder management *(n = 8);* and pressure injuries *(n = 8)*. Each domain was given a page in the survey. Each page began with a brief definition and description of the domain, followed by the strategies for that domain. While traditional Delphi methods are designed for "experts" in a topic, we included definitions and descriptions to ensure *all* respondents could understand the items presented. Descriptions for each strategy were written at a Canadian grade 8 reading level to enhance comprehension of survey content and extend the idea of "expertise" beyond education level. Each strategy was paired with an 11-point Likert scale, where participants could indicate their level of agreement with implementing each strategy (0 = strongly disagree with implementing the strategy; 10 = strongly agree with implementing the strategy). Strategies were randomized within each domain. After presenting all strategies for a domain, participants were given an open textbox to share insights about anything that may not have been included in the strategy list. Open-ended questions are uncommon for Delphis but allowed individuals who could not attend the Summit meetings to share their unique and important perspectives. After survey completion, a separate online link was sent to participants, allowing them to provide consent and contact information for future survey rounds.

Upon completing the initial draft of Survey 1, PA shared the survey with 14 Alliance members with SCI lived experience, and/or expertise in research and/or policy. Sharing the survey with members outside of the immediate partnership allowed the survey to be further refined for accuracy, clarity, and acceptability. Once proposed changes were implemented, Survey 1 was piloted with four members of the Ontario SCI community, and minor refinements were made to create the final version.

Survey 1 dissemination

SCIO staff were responsible for survey dissemination, including any communications associated with the survey (e.g., reminders to complete the survey, social media advertisements). Surveys were disseminated through e-mailing SCIO and Alliance membership databases, website advertisements, and Twitter/Facebook postings. Participants were given two months to complete the survey and received three reminders to complete the survey two weeks, one week, and one day before the survey closed.

Survey 1 analysis

Aligning with traditional Delphi methods, Survey 1 results informed the development of Survey 2. e.g., analyzed the initial survey responses within one week of closing the survey. The mean score, highest score, and lowest score were calculated for each strategy. Strategies were only included in Survey 2 if they met one of two *a priori* consensus criteria: (a) had a mean score greater than or equal to 8.0 *or* (b) had two-thirds of participants rate the strategy as an 8.0 or above (16).

Survey 2 development, dissemination, and analysis

Survey 2 was formatted identically to Survey 1, with the primary difference being that the descriptive statistics (i.e., mean score, highest score, lowest score) and consensus values for each strategy were presented beside each item. With this information, participants are again asked to indicate their level of agreement with each strategy against the same 11-point Likert scale. The link to complete Survey 2 was only e-mailed to participants who completed Survey 1 *and* indicated interest in participating in future consensus surveys. Respondents were given 2 months to complete Survey 2 and were provided with the same three completion reminders prior to the survey closing. At the end of the survey, participants were asked to indicate if they were interested in participating in the in-person retreat, where survey results would be discussed and incorporated into working-group activities. This iterative process of development and analysis was repeated until participants reached consensus on all strategies.

Retreat

To promote meaningful engagement beyond survey completion, PA suggested hosting a one-day in-person retreat within the Alliance's previously scheduled annual meeting. Strategically combining the events ensured that the Alliance was being considerate of their memberships' other commitments and priorities. The retreat consisted of three key events: (1) presentation of survey results, (2) expert panel discussion, and (3) facilitator-led working groups. Seventy-three people, including people with SCI lived experience, researchers, policymakers, and clinicians attended the retreat. Binders with summarized information from the presentation and panel discussion were provided to attendees to be used throughout the day.

Presentation and panel discussion

EG created and delivered a presentation to summarize survey findings: respondent demographics, strategies that did/did not meet consensus, and responses from open-ended questions. Attendees were then able to ask EG questions about the surveys. Following the presentation, PA moderated a panel with the five researcher clinicians who synthesized the evidence used to determine strategies for the survey. Attendees could also ask panel members questions after the discussion, which provided a more comfortable space for people with SCI lived experience to ask questions to individuals they would not normally have the opportunity to ask. Lunch took place after the panel discussion, giving attendees time to digest the information from the morning, and informally network with other attendees.

Facilitated working groups

After lunch, an externally-hired facilitator led all attendees in group-based brainstorming activities that incorporated the survey results. There were eight working groups, with two tables dedicated to each domain. Seating arrangements were determined *a priori*, to ensure tables were a heterogeneous mix of clinicians, researchers, people with SCI, community organization staff, and policymakers. Using pre-determined questions co-developed by PA and the external facilitator, the external facilitator encouraged each working group to collectively engage in critical thinking and discussion. The questions asked included:

- What are the proposals that should be the focus of engagement work by the community?
- What are the things to remember to engage our community over the next 3 years in this work?
- What are the things we should avoid when engaging the community in this work?
- What will the impact of our collective work be at the end of the 3 years?

Each working table was assigned a note-taker and a sub-facilitator to keep the table on-topic and ensure equitable sharing. Facilitators and note-takers were provided with two worksheets (one page with instructions, one page with each question and space below to take notes) to facilitate these tasks and were given time to review the materials before the afternoon's events. Notes from each working group were collected and synthesized to inform specific actions the Alliance should take when developing their strategic plan.

Successes, challenges, and lessons learned

Following the retreat, ten participants from varying perspectives and levels of involvement in the development, dissemination, and/or participation in the consensus method were asked to participate in a semi-structured interview. Five were interviewed (six agreed to participate, one withdrew their responses). The interview guide (Supplementary File S2) asked questions about the successes, challenges, and lessons learned from implementing the consensus method.

Interview analysis

All interviews were audio-recorded, transcribed, and checked for accuracy by EG. Identifying information was anonymized for each transcript. All transcripts were subjected to a collaborative reflexive thematic analysis (28, 29). EG re-read all transcripts and took detailed notes to familiarize themselves with the data. EG then used the interview transcripts and notes to identify initial codes, which were then constructed into draft themes. EG presented the draft themes to PA, HG, and SS, who in their role as critical friends helped to refine, define, and name each theme (30).

Consensus method outcomes and perspectives

Survey reach

Survey 1 was disseminated to over 2,500 members of the Ontario SCI community, including Alliance members (i.e., researchers, clinicians, policymakers); SCIO staff, volunteers, and membership; and peer activists. Table 1 includes detailed demographics for survey participants. In total, 374 people completed Survey 1 (*Mean Age: 54.8 years, 32% female*); with 78% of respondents $(n = 291)$ having SCI lived experience (*24% tetraplegia)* and a response rate of 15%. For Survey 2, 118 people responded (31.6% of Survey 1 respondents) (*Mean Age: 54.7 years, 33% female*), with 74% of the 118 having SCI lived experience *(24% tetraplegia)*. Examples of "other" roles indicated in both surveys included SCI peer mentor, non-profit organization staff or volunteer member, and SCI advocate. Over 70 Survey 2 respondents expressed interest in attending the retreat. For pragmatic reasons (e.g., not all interview attendees who indicated interest in attending came for the event, not all attendees stayed for the entire event), we were unable to collect demographic information from retreat participants. To maintain participant confidentiality, demographic information about retreat participants and interview participants is not presented.

Survey & retreat outputs

Using the findings from the survey and retreat, the Ontario SCI Alliance held a series of meetings to further identify community members' strengths in pushing for implementation of the selected priorities. Examples of noticeable changes that were made as a result of the community-based consensus exercise are presented in Table 2 (31–33).

TABLE 1 Demographic characteristics of survey participants.

Characteristic	Survey 1	Survey 2
Number of participants	$n = 374$	$n = 118$
Age	Mean: 54.8 years	Mean: 54.7 years
Gender		
Male	$n = 255$; 68%	$n = 79$; 67%
Female	$n = 119$; 32%	38; 33%
People with SCI	$n = 276$; 74%	87
Paraplegia	$n = 204$; 74%	67; 76%
Tetraplegia	$n = 71$; 26%	20; 24%
Primary role		
Person with SCI	$n = 187$; 50%	$n = 71$; 60%
Family/friend	$n = 14$; 4%	$n = 3$; 3%
Community service Provider	$n = 26$; 7%	$n = 9$; 8%
Hospital clinician	$n = 11$; 3%	$n = 0$; 0%
Community clinician	$n = 4$; 1%	$n = 2$; 2%
SCI researcher	$n = 7$; 2%	$n = 2$; 2%
Funder or policy maker	$n = 4$; 1%	$n = 0$; 0%
Other	$n = 119$; 32%	$n = 29$; 25%

TABLE 2 Examples of implemented changes from the community-based consensus exercise.

Domain	Description of change	Resource/ reference
Primary care and community supports	Expansion of primary care for people with SCI, including a reduction in wait times for accessing primary care, and increased accessibility for examination rooms	Centre for Family Medicine Mobility Clinic Team (31)
Pressure injuries	Development of a wound care strategy in partnership with the Ontario government	
Bladder management	Creation and finalization of a campaign for public coverage of intermittent catheters and urinary care supplies	#PeeForFree Campaign (32)
All domains	Implementation of educational toolkits top be used for home and community care	Accessed through the SCIO Cortree Educational Series (33)

Successes and challenges of the consensus method

From the reflexive thematic analysis, five core themes were co-constructed to highlight perceived successes and challenges of the consensus method: (1) *Inclusion, Diversity, Equity, and Accessibility (IDEA);* (2) *Partnership;* (3) *Design*, (4) *Transparency and Clarity in Communication; and* (5) *Sustainability.* Supplementary File S3 includes further explanations of each theme supported by interviewee quotes.

Inclusion, Diversity, Equity, Accessibility

Deliberate prioritization of making the consensus method more Inclusive, Diverse, Equitable, and Accessible (IDEA) was integral to the perceived success of the method. Intentionally considering *who* was involved in the consensus exercise, and *how* to meaningfully involve people exemplified how the method supported IDEA. For example, placing "decision-makers" (e.g., government policymakers) at each working group table ensured that someone with the power and authority to induce change heard everyone's thoughts. Multiple methods to facilitate participation were also seen as beneficial for promoting inclusive and accessible decision-making practices. For example, individuals unable to attend the retreat could still meaningfully provide input by completing the survey(s). Additionally, providing opportunities to participate through both a survey *and* a retreat, regardless of role or expertise, encouraged the sharing of multiple and diverse perspectives. The Alliance used accessible language in the survey(s), presentation, and reading materials to increase comprehension, added open-ended survey questions to elicit perspectives outside of synthesized evidence, and pre-assigned working group tables to facilitate multidisciplinary interactions. Finally, the importance of including SCI networks and organizations at each stage of the consensus method was mentioned, as networks/organizations can act as a single entity while representing many community members.

A notable challenge interviewees expressed was that the Hart House was not conducive for the retreat. The Hart House had limited wheelchair parking and limited physical space indoors, creating a barrier by preventing more people with SCI lived experience from participating. Overall, interviewees stressed that the unique needs of people with SCI must be known and well-understood when designing an initiative or event that people with SCI are asked to attend. Examples of considerations included: scheduling later start times to accommodate for time needed for self-care and selecting centrally located events for greater public transit options.

Partnership

Partnering between academic researchers and a community network was considered critical for designing and delivering the consensus method within a short time frame. Favourable features of the partnership included the evident trust between the academic and community partners and that both partners were always thinking about how decisions would benefit both parties.

Conversely, some interviewees felt the partnership was missing perspectives from industry organizations, which may have limited the retreat's potential. It was mentioned that academics and non-profit organizations may not be as well trained as the for-profit industries in hosting events to share research with diverse audiences. A second challenge interviewees discussed was that timelines and priorities for academia and communities differ and can conflict. Specifically, community organizations' priorities change to reflect the needs of their membership at a rate that may not align with institutional requirements for university-based research projects (e.g., ethics board approvals, time for applications and manuscripts to be reviewed).

Design considerations

Incorporating qualitative questions in the survey(s) (i.e., open-ended questions) was praised by interviewees as it allowed respondents to share opinions that did not align with the Likert scale question options. Grounding the development of the survey in Delphi methodology was also praised by interviewees, as it allowed for information to be presented systematically to facilitate simpler decision-making processes. Interviewees highlighted two specific decisions that contributed to the high turnout and level of engagement at the event: location of the event and the use of an external facilitator. The Hart House, located in Toronto, the largest city in Ontario, Canada, acted as a central public transit hub and ensured attendees had several options to get to the event. Interviewees commented that hosting the presentation and panel in a smaller room within the Hart House may have bolstered people with SCI's confidence in asking questions to researchers/clinicians, where a power dynamic is usually present. Finally, hiring an external facilitator to lead the working group tables was highlighted as a strategy to ensure all attendees were comfortable sharing opinions, regardless of their roles or expertise.

Conversely, some interviewees felt that hosting the event at Hart House may have impeded inclusive decision-making processes. Some individuals were unable to attend the retreat due to capacity limits or an inability to get to the event (those from rural/remote communities), meaning these individuals' insights were not heard or included during the working group tables.

Transparency and clarity in communication

The need for transparent and clear communication by the partnership to survey and retreat participants was discussed by almost all interviewees as critical for promoting engagement and trust.

Interviewees highlighted how the purpose of the survey(s) and retreat was communicated very transparently to the Alliance members involved in refining the survey, and retreat participants with more active roles (i.e., presenters, panel members, external facilitator, table facilitator(s), note-taker(s)). However, communication about the event's purpose could have been clearer and more transparent to other survey and/or retreat participants. Interviewees also expressed that clearer communication about *who* was involved during each stage of developing the consensus method (e.g., Summit participation, survey development and dissemination, retreat activities) may have promoted more engagement by ensuring people knew whose perspectives informed each stage.

When asked how communication could be improved, interviewees recommended that decision-making could be further simplified if a guiding framework was used to explain to survey and retreat participants the different ways they could be involved in the method (e.g., the Spectrum of P2) (34).

Sustainability

The importance of strategizing how to formalize the consensus method was discussed, as formalization would likely allow for the method's use in guiding future decision-making processes for the Alliance. Some interviewees felt the method itself was evidence of shared decision-making at a community level, and that presenting the method and its impact in academic formats (e.g., conference presentations, peer-reviewed journals) would ensure funding organizations viewed the method as rigorous and evidence-based. Involving a graduate student trainee was also viewed as critical in ensuring the sustainable use of the consensus method. Involving trainees as co-leads in the partnership ensured that the values of partnering and meaningful engagement are instilled early in one's career, and maintained as trainees transition into independent researchers.

An inability to maintain the same level of communication with participants *after* the retreat, as was done *during* the surveys, was viewed by interviewees as a challenge for sustaining the engagement and impact of the method. An effort that could have been undertaken to promote sustainability included updating the membership on how the selected strategies are being implemented. However, interviewees also indicated that ensuring receipt and understanding of these updates by participants would be difficult to monitor and address.

Discussion

Our academic-community partnership co-designed a community-based, consensus method to harness the opinions and perspectives of the Ontario SCI community to inform research and policy-based decisions. The method consisted of two modified Delphi surveys and one in-person retreat; all of which were well attended by members of the Ontario SCI community, in particular people with SCI lived experience. Following the retreat, the Ontario SCI Alliance synthesized the survey and retreat materials to inform their strategic plan and deliver relevant policy changes for their membership. Five themes around successes, challenges, and lessons learned from the method were co-constructed from our collaborative reflexive thematic analysis: (1) *Inclusion, Diversity, Equity and Accessibility* (*IDEA*); (2) *Partnership*; (3) *Design Considerations;* (4) *Transparency and Clarity in Communication*; and (5) *Sustainability*. These themes highlight key factors to consider when co-designing and implementing a community-based consensus method.

Survey development and dissemination

Modifying our approach rather than adhering to the prescriptive criteria of traditional Delphi exercises aligns with previous efforts of research users with differing needs and priorities to arrive at consensus (35, 36). Including a retreat was similar to previous modifications (e.g., online discussion, workshops, focus groups). However, modifying the survey questions and incorporating qualitative, open-ended questions is less common practice. This intentional decision helped facilitate inclusion and break down knowledge hierarchies by allowing for anecdotal, lived experience to be considered with the same weight as evidence-informed strategies during decision-making. Considering that attention to inclusion has rarely been noted in the consensus literature (10), this reproducible strategy can support researchers and communities to promote inclusion during consensus exercises.

Preparing and conducting consensus methods in partnership is not novel, but partnership guidance for groups to refer to remains limited (10). Delphi guidance primarily targets traditional methods, and internal modifications to consensus methods are rarely reported with transparency or detail, making reproducibility and an understanding of participants' roles in a Delphi difficult. To address this qualm, we transparently report on our method's preparation, conduct, and analysis through our diverse partners' perspectives (Supplementary File S1) and highlight challenges that arose (e.g., tight timelines for funding applications). We hope providing highly detailed and transparent reporting may help normalize the reporting process, make modified Delphi exercises more reproducible, and provide valuable information that can be used to develop and evaluate acceptable criteria for modified Delphi exercises.

Previous guidance recommends six "expert" participants as the requirement for a Delphi to be a reliable consensus method (37). While 374 participants exceeded this recommendation, our overall response rate was only 15% as the survey was disseminated to over 2,500 people. Seventy percent is suggested as a desirable rate for maintaining rigour in a Delphi exercise, though this guidance is specific to a Delphi with 6–30 experts (38, 39). Previously established Delphi recommendations may not be appropriate for community-based Delphi methods, given the distinct differences in the number of participants. Future research should focus on expanding and evaluating Delphi criteria to accommodate and engage more participants.

Booking the retreat at a small venue facilitated more intimate conversations. However, this decision ran the risk of tokenizing the people with SCI in attendance, particularly if efforts were not undertaken to mitigate power dynamics during decision-making conversations (40). Since our retreat, the COVID-19 pandemic has normalized virtual/hybrid engagement efforts, which would likely simplify implementing virtual engagement supports to accommodate for travel restrictions and varying levels of comfort with in-person interactions. Future studies should explore if and how virtual engagement changes any of the method's outcomes or impacts.

Successes, challenges, and lessons learned

Prioritizing IDEA throughout the stages of the consensus method fostered meaningful participation from diverse perspectives of the Ontario SCI community. Certain strategies adopted by our team have previously been used to mitigate power dynamics and maximize participation throughout the consensus process, including external facilitators (41, 42) and scheduling the retreat alongside an annual meeting (43). Our findings add to the literature by suggesting specific strategies for promoting meaningful engagement with people living with SCI (e.g., using surveys to prevent inflexible participation times; later start times to accommodate for self-care tasks) that can guide researchers and policymakers to make their processes more inclusive and accessible for people with SCI specifically. However, we caution that adopting these strategies does not automatically translate into *full* inclusion, diversity, equity, and accessibility for people with SCI. Rather, the strategies can be undertaken to adopt *more inclusive, accessible, equitable and diverse* practices. Full "IDEA" cannot be achieved, as understandings of IDEA are different and even conflict with one another, based on one's unique intersectional identity and environment (44, 45).

Attribution of the method's success to a strong academic-community partnership is not unexpected, as the science of research partnerships has advanced since our work in 2018. Published in 2021, a multidisciplinary panel of SCI researchers, research users, and funders rigorously co-developed the Integrated Knowledge Translation Guiding Principles for Conducting and Disseminating Research in Partnership (4), which outline eight values for all research partners to follow early and throughout the research process. Our findings can further advance the science and use of these principles by proposing observable, actionable

TABLE 3 IKT guiding principles with example strategies adopted by our partnership.

Principle	Example of strategy
1. Partners develop and maintain relationships based on trust, respect and dignity	PA and HG have a previously developed partnership that began in 2013. Through transparent communication and regular check-ins with on another, trust was developed between them, allowing them to engage in a second research project within their partnership.
2. Partners share in decision-making	Decisions at each stage of the project were made collectively by all partners, and the project did not move forward unless all partners had a meaningful say in the final decision (see Supplementary File S1).
3. Partners foster open, honest, and responsive communication	All partners were aware of each other's preferred communication methods and engaged in all project communication using these methods to ensure responsiveness.
4. Partners recognize, value, and share their diverse expertise and knowledge	PA's unique and extensive knowledge of SCI through his lived experience and time working with SCIO and the Alliance was shared with all partners, and incorporated throughout the methods (e.g., which domains to include in the survey, who to disseminate the survey to).
5. Partners are flexible and receptive in tailoring the research approach to match the aims and context of the project	Changes were made to the Delphi method protocol to match the aim and context of the project Aim: To ensure that this was a "community-based" Delphi, the number of "experts" was not limited in terms of the number of participants, or their "knowledge/expertise" in the subject. Context: Traditional timelines for the Delphi were modified to accommodate for the Alliance's deadline in creating their strategic plan.
6. Partners can meaningfully benefit by participating in the partnership	Academic partners: outputs of this project have aligned with indicators for academic merit (a successful grant application, 2 poster presentations at academic conferences, 1 peer-reviewed manuscript, 1 national trainee award). Community partners: outputs of this project resulted in an evidence base that could be used to inform the Alliance's upcoming decisions for research implementation over a 3 year period.
7. Partners can address ethical considerations	Given the unique roles within the Ontario SCI community, it can be easy to identify participants' throughout the Delphi. Throughout surveys and interviewing, all partners strategized how we can maintain participant confidentiality while meaningfully disseminating results.
8. Partners respect the practical considerations and financial constraints of all partners	The MITACS funding opportunity was selected to fund this project as it supported the Alliance (a non-profit entity) to hire a trainee to complete work without impacting the organization's operations, while ensuring EG was compensated appropriately for her time and efforts.

strategies that can support partnerships to follow specific principles (Table 3). Additionally, our findings demonstrate how SCI research partnerships can integrate policy-making with research. Future research efforts should focus on how principles and strategies for policy-focused partnerships may differ from the current research partnership literature.

Our third theme, Transparency and Clarity in Communication, aligns with Principle 3 of the IKT Guiding Principles: *Partners foster open, honest, and responsive communication.* Considering only challenges were discussed within this theme, it is likely that our interview participants greatly value strong communication within and beyond the partnership, and wanted to ensure that efforts to improve communication were vocalized. Potential reasons that communication to participants may not have been as meaningful include the tight timeline for designing and conducting the method in order to accommodate the Alliance's needs. Previous scholars have emphasized the importance of recognizing the time and effort needed to execute a consensus method in a meaningful and engaging way (43). In thinking about meaningful communication with people with SCI, previous research has examined preferred communication methods for other topics, such as physical activity messaging (46) and peer mentorship (47). Similar efforts to understand preferred communication methods and timelines are likely needed to improve policy-based decision-making with people with SCI.

A critical future direction from our work is involving trainees as co-leads in research partnerships to normalize and motivate others to partner meaningfully with equity-deserving groups. We provide a detailed account of a trainee's capacity to hold a leadership role in a research partnership that also explains strategies for addressing issues that arose. Our work adds to previous efforts by Nguyen and colleagues regarding trainee involvement in partnerships (e.g., it is okay to not know what a partnership looks like; there is no single recipe for how to partner; take time to invest in partnerships; provide ongoing opportunities to reflect; consider balancing power dynamics and incorporating diversity) (48). EG was also awarded the national Mitacs Award for Outstanding Innovation as a Master's student for this project, suggesting that funding bodies are prioritizing partnerships with equity-deserving communities. Our work can help to inform efforts to advance the capability of trainees to partner with equity-deserving groups.

Strengths and limitations

A notable strength is the absolute number of individuals who participated in the surveys and retreat. To our knowledge, this is the highest number of individuals with SCI to meaningfully participate in a Delphi for making policy-based decision-making. Second, conducting the consensus method in partnership allowed for research, clinical, policy, and SCI lived experience perspectives to be meaningfully incorporated while designing the survey(s) and retreat, which has helped to increase the relevance of the strategies included in the surveys, and strategies discussed during the retreat.

While our partnership did follow other evidence-based strategies to improve response rates, such as sending reminder e-mails, additional efforts could have been undertaken to improve response rates, such as clearer explanations of the study process and the importance of commitment throughout the surveys and providing incentives for completing surveys (38, 39). Second, as we were unable to collect demographic data on retreat participants, we cannot make any inferences regarding how attendees' demographics may or may not have impacted their retreat experiences. Third, e.g., delivered the presentation at the retreat. Given their role as a trainee, EG may have been uncomfortable probing further into negative comments about the consensus method, or interviewees may not have wanted to share negative thoughts with EG Fourth, our conceptualizations of IDEA were framed by individuals and organizations working to combat ableist societal views. As such, our proposed strategies for promoting IDEA cannot be assumed to address *all* systems of inequity (e.g., sexism, racism, etc.). Future efforts to implement and evaluate consensus-based methods should adopt an intersectional lens to ensure that multiple inequities are considered when developing strategies to promote IDEA. While not a methodological limitation, the retreat occurred before the COVID-19 pandemic, and any claims from our findings that signify the importance of using in-person methods were not made with knowledge of the pandemic.

Conclusion

Our academic-community partnership co-developed a community-based consensus method that meaningfully engaged a large SCI community in determining research and policy decisions. While there are still challenges to address, our detailed account of the development, dissemination, and execution of the method can support other organizations/networks that represent equity-deserving groups to meaningfully engage those with lived experience in their decision-making processes.

Data availability statement

Raw data will be made available upon reasonable request.

Ethics statement

The studies involving humans were approved by University of British Columbia Okanagan Behavioural Research Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

EG: Conceptualization, Data curation, Formal Analysis, Investigation, Methodology, Resources, Writing – original draft, Writing – review & editing. PA: Conceptualization, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – review & editing. SS: Formal Analysis, Investigation, Methodology, Resources, Supervision, Writing – review & editing. HG: Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Resources, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

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Towards co-design of rehabilitation technologies: a collaborative approach to prioritize usability issues

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Introduction: Early stakeholder engagement is critical to the successful development and translation of rehabilitation technologies, a pivotal step of which is usability testing with intended end-users. To this end, several methods employ end-user feedback to identify usability and implementation issues. However, the process of prioritizing identified issues seldom leverages the knowledge and expertise of the range of stakeholders who will ultimately affect the demand and supply of a device. This paper describes a novel method to prioritize end-user feedback using transdisciplinary stakeholder consultation and address it in subsequent product development. The proposed approach was demonstrated using a case study relating to the development of a novel technology for neural recovery after spinal cord injury.
Method: Feedback from five individuals with chronic spinal cord injury was collected during two-hour usability evaluation sessions with a fully functional high-fidelity system prototype. A think-aloud and semi-structured interview protocol was used with each participant to identify usability and acceptability issues relating to the system in a 3-phase approach. Phase 1 involved extracting usability issues from think-aloud and semi-structured interview data. Phase 2 involved rating the usability issues based on their significance, technical feasibility, and implementation priority by relevant internal and external stakeholders. Finally, Phase 3 involved aggregating the usability issues according to design and implementation elements to facilitate solution generation, and these solutions were then raised as action tasks for future design iterations.
Results: Sixty usability issues representing nine facets of usability were rated. Eighty percent of issues were rated to be of moderate to high significance, 83% were rated as being feasible to address, and 75% were rated as addressable using existing project resources. Fifty percent of the issues were rated to be a high priority for implementation. Evaluation of the grouped issues identified 21 tasks which were mapped to the product roadmap for integration into future design iterations.
Discussion: This paper presents a method for meaningful transdisciplinary stakeholder engagement in rehabilitation technology development that can extended to other projects. Alongside a worked example, we offer practical considerations for others seeking to co-develop rehabilitation technologies.

KEYWORDS
usability testing, technology, rehabilitation, disability, co-design

1 Introduction

The role of technology in rehabilitation has attracted significant attention based on its potential to enhance therapeutic outcomes (1). For effective translation of rehabilitation technologies, the design and development process should be iterative and multidisciplinary. At a minimum, it should involve the stakeholders who will ultimately use or endorse the device (2–4). A critical step within this process involves end-users testing the usability of developed prototypes, where usability is defined as ease-of-use (5) or "*the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use*" (6, page 68). Issues identified through usability testing with intended users, who likely think and act differently than technical experts, can inform design variations required to meet user needs and raise valuable considerations for the translation and implementation of the tested prototype in environments outside of the design and development space (7, 8). While several methods are available for identifying usability and implementation issues through the consultation of end-users (9–15), approaches to rating the criticality or priority of resolving these issues are traditionally undertaken less collaboratively.

The process of prioritizing identified issues is typically undertaken by technical experts based on objective user performance metrics (e.g., task success, time on task, errors, efficiency, and learnability) and frequency of issue occurrence (e.g., frequencies of issues within and across tasks, percentage of participants who experience a particular issue) (16). In parallel, the availability of technical expertise or project resources (e.g., personnel, funding, time) is considered (17). However, prioritization of issues in these ways lacks consideration of the quality of the user experience and does not account for the perspectives of pivotal stakeholders who have the potential to influence the demand and supply dynamics of technologies (16, 18). We instead argue that user feedback should be prioritized for integration into product design by additionally considering the impact of the design improvement on the cognitive and affective user experience (e.g., attitude towards device use, impact of device use on mood). User perceptions of the social and practical acceptability and utility of a device should also be considered during issue prioritization (5, 18, 19). Managing these numerous and sometimes competing priorities can be challenging, particularly when attempted in isolation by a single stakeholder group. Despite innovations including user-centred design, technical experts (e.g., engineers, designers) rarely have the lived experience necessary to represent users' point of view, while users rarely have the information or expertise necessary to understand the contextual factors impacting issue resolution (18, 19).

One way to address this challenge is to engage a wider range of technical and non-technical stakeholders in the prioritization of issues identified through usability testing (20, 21). Ongoing stakeholder consultation is consistent with co-design methodologies, in which diverse stakeholders are collaboratively engaged in design and development (2–4, 22). Through collaboration, stakeholders' experience and expertise can be leveraged to reconcile the numerous and competing priorities for implementation in future design variations. Collaborating in this way requires open communication and transparency in decision-making between stakeholder groups to ensure design iterations are clearly linked to user feedback. In this paper, we propose a novel method to prioritize user feedback through stakeholder consultation and to integrate this feedback into future product iterations in the context of rehabilitation technologies. In this approach, transdisciplinary stakeholder consultation refers to the inclusion of stakeholders in participatory problem-solving approaches that are applied to tangible, real-world problems (23). The proposed method is described and demonstrated using a case study based on the development of a technology for neural recovery after spinal cord injury. Significance, technical feasibility, and implementation priority ratings were collaboratively assigned to user-identified issues determined through a think-aloud and semi-structured interview protocol. Issues were subsequently grouped for the purpose of solution ideation and ratings were used to integrate solutions in the project's product roadmap. A worked example is included as part of the case study that demonstrates the process of identifying, prioritizing, and addressing one identified usability issue in the context of the product roadmap for the described technology.

2 Materials and methods

The usability evaluation described in this paper forms one component of a larger research project developing a novel system for neural recovery after spinal cord injury (24). The project team comprised of three key bodies: internal Design and Translation Teams, and a Steering Committee of external stakeholders. A three-phase process (Figure 1) was undertaken collaboratively by these teams to collect and analyze usability data for issue identification (Phase 1), rate the significance, technical feasibility, and implementation priority of identified usability issues (Phase 2), and generate solutions to improve system usability and acceptability (Phase 3). Phases 2 and 3 are the focus of this paper. This process was developed collaboratively by-, and utilized the transdisciplinary expertise of- the Design and Translation Teams and Steering Committee members, which spanned lived experience of disability (including people with disability and formal and informal carers), health (including medical, allied health), neuroscience (including brain-computer interfaces and biomechanics), engineering (including robotics), design (including game and industrial), and policy (including legal policy and insurance).

This study was approved by the local ethics committee (Griffith University, reference number 2019/994).

2.1 Neurorehabilitation system

The system used as an example in the case study presented was a prototype of medical device with Technology Readiness Level 5, wherein the main technological components were integrated in a configuration similar to the final target application and tested in

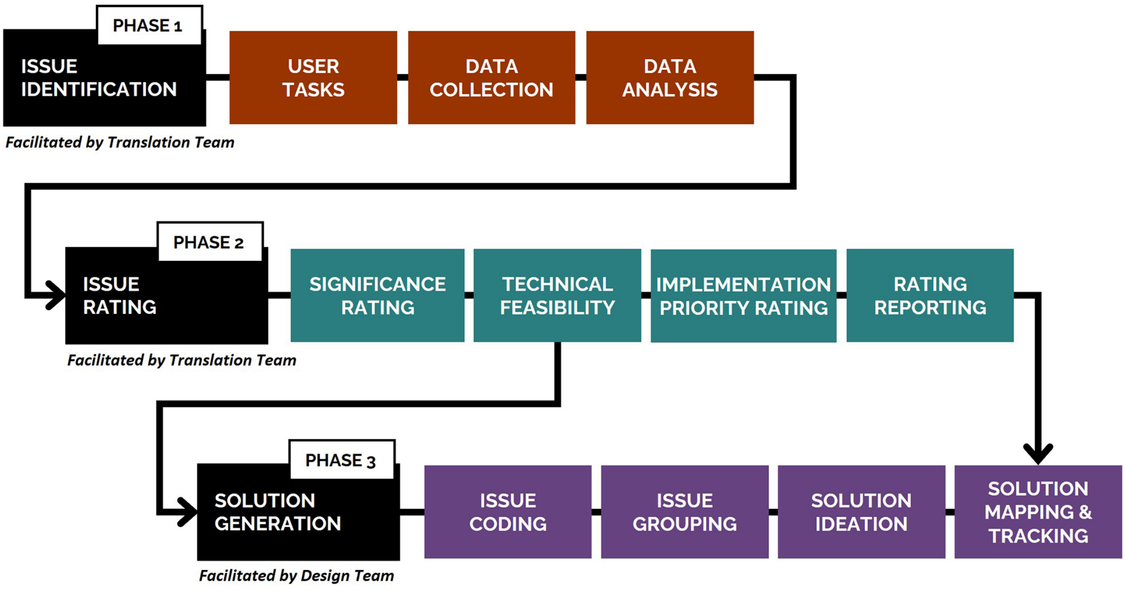


FIGURE 1
Three-phase process undertaken to collect and analyze usability data (Phase 1), rate identified usability issues (Phase 2), and generate solutions to improve system usability and acceptability (Phase 3). A detailed description of Phase 1 of the study, including the methods for the think-aloud and semi-structured interview protocols, has been published elsewhere (25).

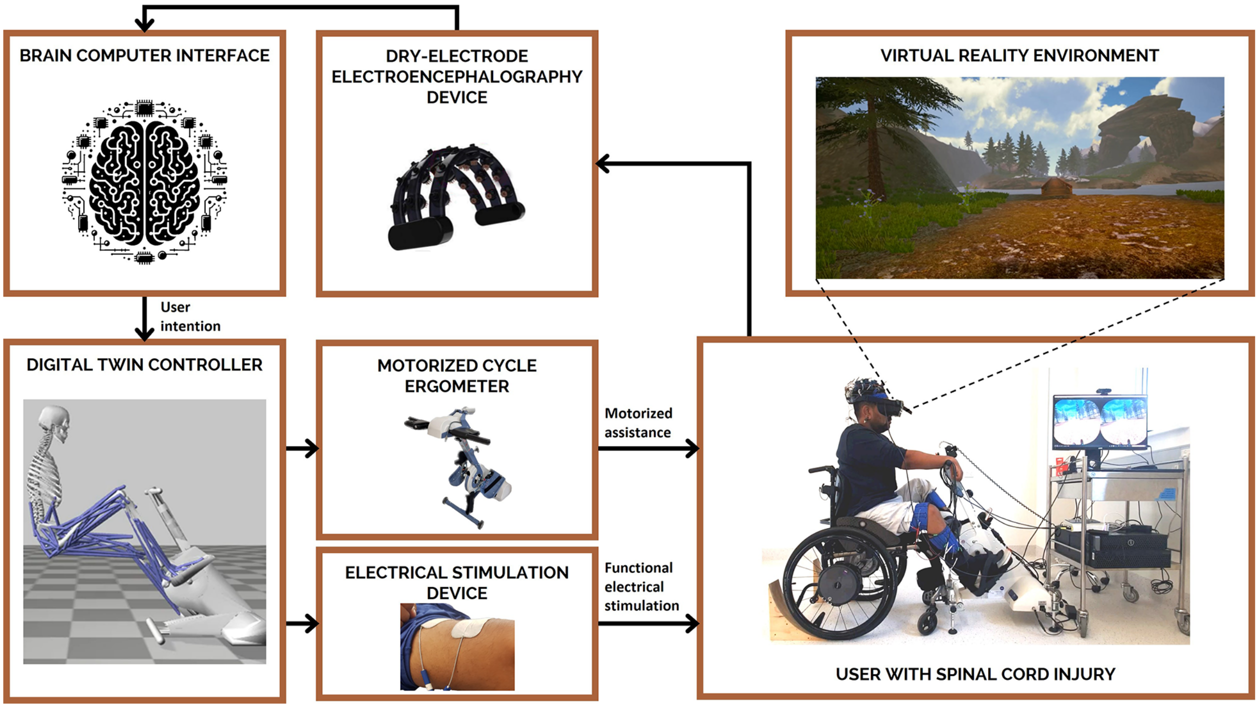


FIGURE 2
The system used in this case study combines non-invasive technologies to enable individuals with spinal cord injury to use their own thoughts (via a brain-computer interface; BCI) to control their own muscle(s) (via functional electrical stimulation; FES) and receive appropriate visual feedback (via virtual reality; VR) to engage in lower-limb rehabilitation (motorized cycle ergometer). Tasks included in usability testing were representative of a typical training session using the system prototype under the supervision of a trained clinician for a period of approximately two hours.

ecologically valid settings. The system followed a proposed framework for the establishment of a digital-twin based approach for interfacing rehabilitation devices to the individual's sensorimotor system (26, 27) and associated standards for the integration of this technology to Health Care (28). A representation of the system is included in Figure 2. In brief, the

TABLE 1 Organization of the 60 identified usability issues related to the design and implementation of the technology and representing nine themes or facets of usability.

Facets of usability (themes)	Number of usability issues	Issue ID
Difficulties engaging with system training	13	#33–45
Comfort and positioning	12	#21–32
Safety and risks	9	#12–20
Knowledge and understanding	7	#1–7
User requirements (expertise and physical function)	6	#55–60
Commitment required to participate in a trial	5	#46–50
System issues and interruptions	4	#8–11
Outcome measurement approaches	3	#52–54
Accessibility of the physical space	1	#51

system enables a person with spinal cord injury to interface with rehabilitation technologies via a non-invasive brain-computer interface. The motor intention of the user is therefore converted, via a personalized digital twin of the person and the connected devices (26, 29), into control signals for the activation of muscle electrical stimulation and motorized assistance. Synchronous first-person view of the person, deployed into an engaging virtual environment, was also provided via immersive virtual reality. The rehabilitation system was developed following quality management system standards (ISO 13485) for medical devices. A key requirement of this standard is the documentation of design modifications, mandating a description of the change, its rationale, and its potential impact on the device. Stakeholder-identified issues during co-design offered valid justifications for these changes, which were meticulously recorded for traceability.

2.2 Phase 1: usability testing

Individuals with a spinal cord injury who had experience using functional electrical stimulation and cycle ergometers were recruited using purposive sampling through the researchers' networks. Five individuals with a spinal cord injury (100% male; mean age = 32.6 years; mean time since injury = 7.3 years) were recruited to attend a typical training session using the system prototype under the supervision of a trained clinician in a university research lab located in Queensland, Australia for a period of approximately two hours. Participants were compensated for their time with an AUD $80 gift card and reimbursed for travel expenses. Concurrent and retrospective think-aloud methods, in combination with a semi-structured interview, were used to capture participants' thought processes and perceptions of the system (9, 11). In Phase 1, a four-step approach was utilized to extract usability issues from video-recorded think-aloud and semi-structured interview data: (1) data logging where data from the think-aloud and semi-structured interview protocol were logged at an individual participant level; (2) initial classification and coding where data were classified as an issue, positive, strategy or "other", with similar data logged within and across participants; (3) higher-level categorization where codes were aggregated into higher-level categories based on their inter-relationships; and (4) theme generation where higher-level categories were organized into themes that reflected the facets of usability or the system component they related to. The application of this four-step approach resulted in the identification of 60 usability issues related to the design and implementation of the technology and representing nine themes or facets of usability (Table 1). Phase 1 was carried out by three members of the Translation Team, with support from technical staff. A detailed description of Phase 1 of the study (Figure 3), including the methods for the think-aloud and semi-structured interview protocols has been published elsewhere (25).

2.3 Phase 2: issue rating

To prioritize usability issues for subsequent integration into the device's roadmap, issues passed through a three-step rating process in Phase 2 (Figure 4), which utilized the expertise and lived experience of members of the project team and external stakeholders. For the current study this included the project's Translation Team, Design Team, and Steering Committee (Figure 5). The rating process was led by three members of the Translation Team, two of whom facilitated the group-based significance and technical feasibility rating sessions. At the conclusion of this process, a report was provided to the Design Team detailing the identified usability issues and their respective ratings, with both visually mapped to facilitate interpretation and subsequent decision-making. Collated information relating to the rating scales is presented in Appendix 1.

2.3.1 Significance rating

The significance of each usability issue encountered was rated by stakeholders with appropriate expertise to understand the significance of the issues on the experience of users with spinal cord injury and clinicians facilitating use. In the current study, this included five members of the project's Translation Team (Figure 4, Significance Rating), including the two members that facilitated the rating session. Translation Team members had lived experience of disability, as well as expertise in disability and rehabilitation research and related fields including health, neuroscience, and engineering (Figure 5). The significance rating was conducted during two online synchronous sessions. To inform their rating, the Translation Team were presented with all identified usability issues and the number of participants who encountered each issue.

The actual or potential significance of each usability issue on users' experience was rated on a four-point scale: minor (minor issue experienced by participant when using the system); moderate (moderate delay, frustration, or discomfort experienced by participant when using the system); severe (significant delay, frustration, or discomfort experienced by participant when using the system); and critical (participant was unable to use the system). In the current study, significance ratings were decided on using a consensus approach via discussion with all attending Translation Team members.

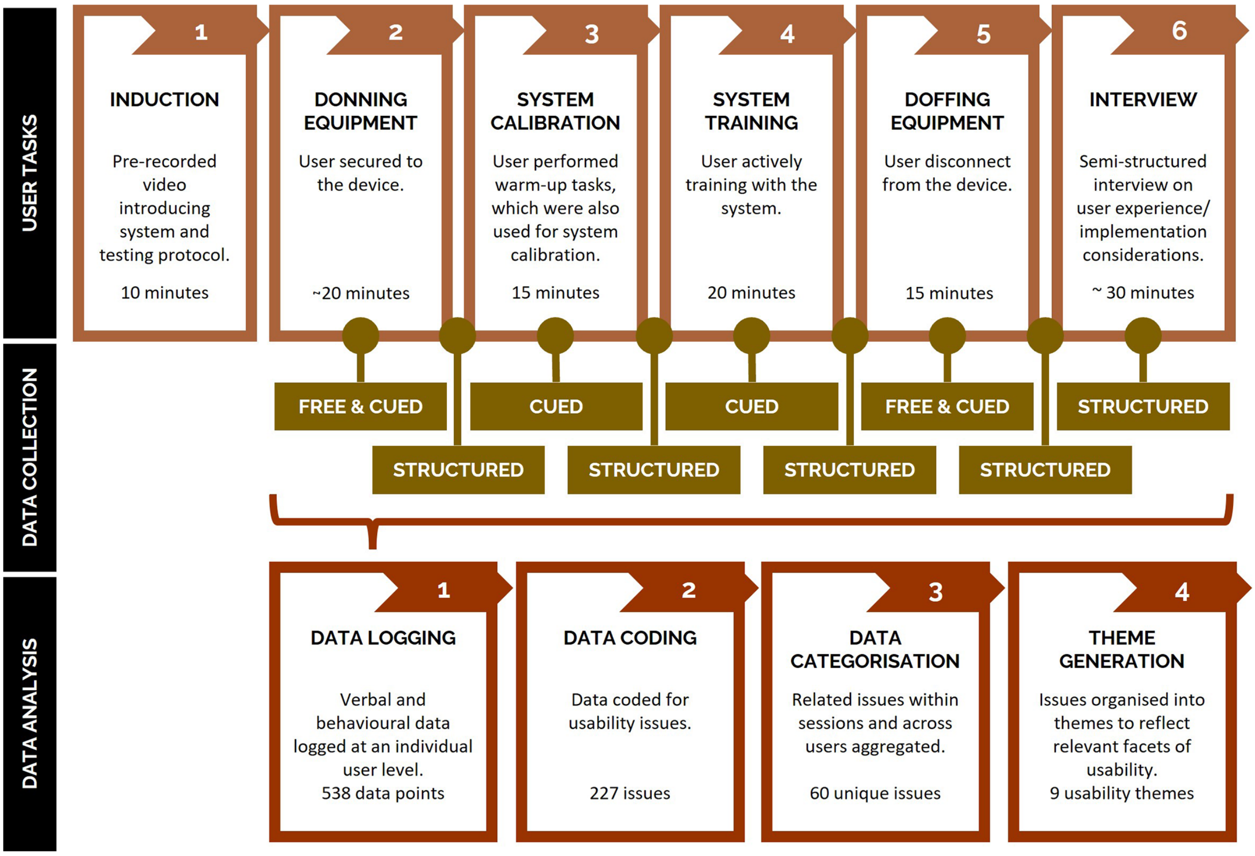


FIGURE 3
Overview of the process of identifying usability issues in Phase 1, including the tasks completed by users during testing sessions (top row; representative of a typical training session), think-aloud and semi-structured interview data collection methods utilized across tasks (middle row), and data analysis methods to extract usability issues from collected data (bottom row). Free = Free or unprompted thinking-aloud during system use. Cued = Cued or prompted thinking aloud during system use (e.g., 'can you tell me what you're thinking'). Structured = Structured or semi-structured questions asked to users after each phase. Device = neurorehabilitation system described in Section 2.1.

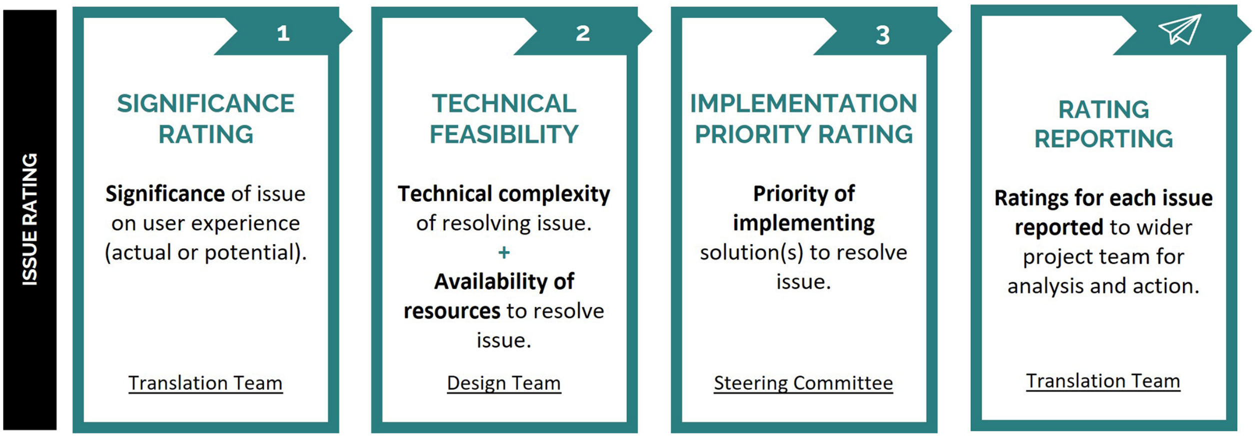


FIGURE 4
Overview of the process undertaken to prioritize user feedback in Phase 2. Each identified usability issue was provided with significance, technical feasibility, and implementation priority ratings, with final ratings reported to the Design Team for analysis and action.

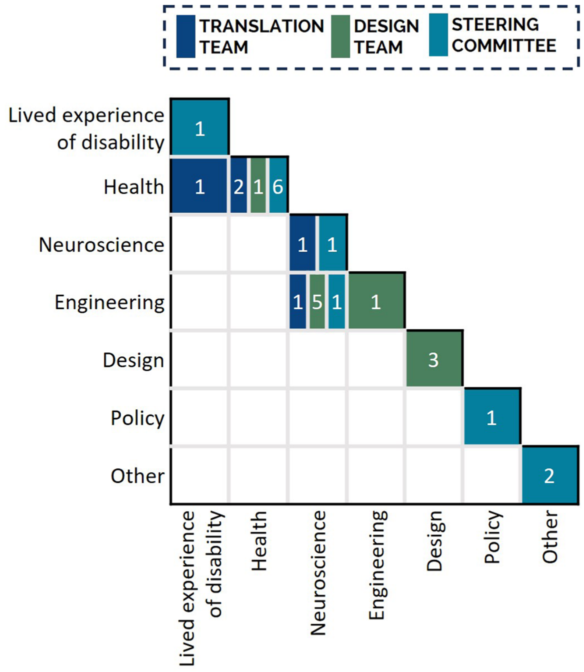


FIGURE 5
Expertise and lived experience of the Translation Team ($n = 5$), Design Team ($n = 10$), and Steering Committee ($n = 12$) members involved in usability issue rating. Nineteen team members indicated expertise in a single discipline; eight team members indicated expertise in two disciplines. All Translation Team members had expertise in disability and rehabilitation research. To interpret the Figure the reader is required to read both the column and row description to identify the expertise of the group of individuals included in the overall cell, then apply the color coding to determine the distribution of this expertise across the three stakeholder groups. For example, there were 7 individuals in total who identified joint expertise in neuroscience and engineering: 1 from the Translation Team, 5 from the Design Team, and 1 from the Steering Committee.

2.3.2 Technical feasibility ratings

The technical feasibility of resolving each usability issue was determined through consultation with technical stakeholders who had the expertise to understand the technical complexity of addressing each issue and knowledge of the project resources available to address each issue. In the current study, this included ten members of the project's Design Team (Figure 4, Technical Complexity), who had diverse expertise across medical, neuroscience, engineering, and design fields (Figure 5). The Design Team were presented with the 60 usability issues and associated significance ratings during a single in-person session. Technical feasibility was comprised of two ratings: technical complexity and resource availability.

The technical complexity of resolving identified usability issues was rated on a four-point scale: minimal (resolving the issue is easy from a technical perspective); moderate (resolving the issue is moderately complex from a technical perspective); difficult (resolving the issue is difficult from a technical perspective); or not feasible (resolving the issue is not technically feasible with technology at that time). A binary resource availability rating (yes, no) was used to indicate whether the usability issue could be resolved with existing project resources (time, equipment, expertise, finances, etc.). In the current study, technical complexity and resource ratings were decided using a consensus approach via discussion with all attending Design Team members, which was facilitated by two members of the Translation Team.

2.3.3 Implementation priority rating

The implementation priority of each issue was determined by stakeholders from a wide range of stakeholder groups relevant to the development and implementation of rehabilitation systems. Stakeholders were external to the system development to allow for more independent evaluation of priority. In the current study, twelve external stakeholders comprising the project's Steering Committee were consulted to provide an independent evaluation of usability issues by assigning an implementation priority rating (Figure 4, Implementation Priority Rating). Steering Committee members represented a diverse set of stakeholders in rehabilitation technology, with lived experience of disability and expertise in the fields of health, neuroscience, engineering, and policy (Figure 5). Usability issues were summarized alongside their significance and technical feasibility ratings for presentation to the Steering Committee. Due to their availability, each Steering Committee member provided an independent implementation priority rating via an online survey (programmed using the platform REDCap, RRID:SCR_003445).

The priority of implementing solutions to resolve identified usability issues was rated on a four-point scale: not a priority (resolving issue is unnecessary and/or unfeasible); low priority (issue to be resolved over the long-term i.e., after the next 9 months and using future project funding); mid priority (issue to be resolved in the short- to mid-term i.e., in the next 6–9 months and before completion of current project funding); or high priority (issue to be resolved immediately or in the short-term i.e., in the next 6 months). In the current study, final implementation priority ratings were determined via the median rating for each usability issue.

2.4 Phase 3: solution generation

Following the technical feasibility rating process in Phase 2, a process was undertaken to determine potential solutions to the identified issues and prioritize these solutions for implementation in the product roadmap. In the current study, the Design Team began a four-step workflow (Figure 6) to review each usability issue and subsequently raise action tasks in the product roadmap for future integration into the system. Phase 3 was led by two members of the Design Team, one of which participated in Phase 2 ratings.

The Design Team analyzed the 60 usability issues, applying a codification system to identify the technology's corresponding sub-system or component (Figure 6, Issue Coding). Codification facilitated subsequent consolidation of usability issues into design

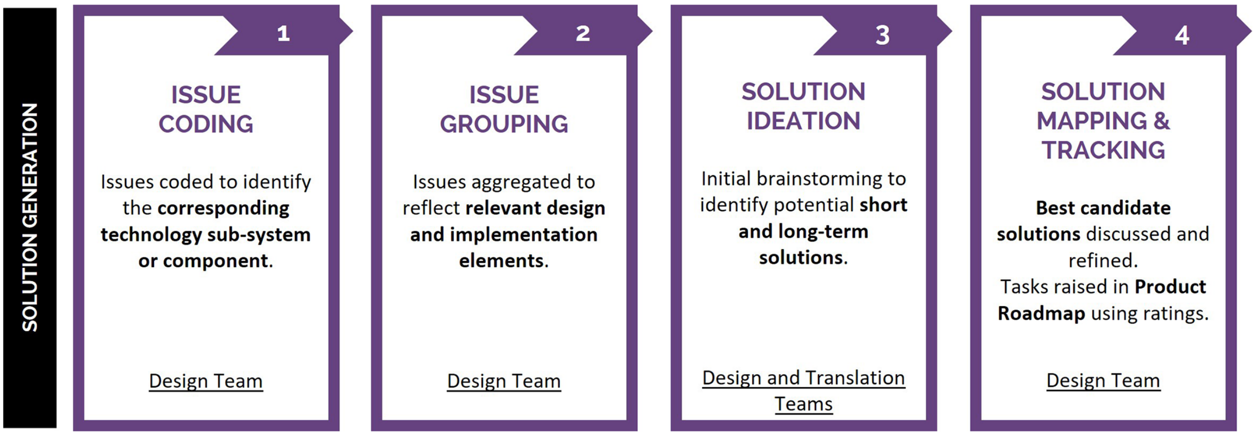


FIGURE 6
Phase 3 solution generation workflow, employed to assess the 60 identified usability issues. Issues were coded and grouped to reflect affected system design and implementation elements and subsequently facilitate solution generation, with resulting tasks raised in the product roadmap for future design iterations.

and implementation elements associated with user-feedback (Figure 6, Issue Grouping), which were the focus of solution ideation. Over the course of five weeks, the Design Team held three, three-hour breakout workshops wherein potential short- and long-term solutions were ideated through open discussion with members of the Design and Translation Teams (Figure 6, Solution Ideation). Workshop attendees included one individual with lived experience of disability and members with diverse expertise across the fields of health, neuroscience, engineering, and design. Initial brainstorming identified potential short- and long-term solutions, with members from both the Design ($n = 12$, two of which had not participated in Phase 2 ratings) and Translation ($n = 2$, who had facilitated Phase 2 ratings) Teams contributing. All ideas were recorded. Design Team subject matter experts then refined best candidate solutions for their delegated design and implementation elements. Best candidate solutions were mapped into the product roadmap for integration into future iterations of the technology (Figure 6, Solution Mapping and Tracking). Product roadmap tasks were finalized after Phase 2 ratings were reported and therefore were informed by the significance, technical feasibility, and implementation priority ratings. Tasks associated with high significance ratings were prioritized for initial development, specifically usability issues deemed to impact user safety, comfort, and experience. Within this subgroup of usability issues, relevant technical complexity, and resource availability factors—such as the number of staff working on a sub-system, their existing workload, time availability, the number and complexity of existing tasks slated for priority development at the time, etc.—were taken into consideration when defining the implementation timeline for product roadmap tasks. Implementation ratings provided independent, external stakeholder input into prioritizing resolution of usability issues, used to further inform/support product roadmap timeline.

3 Results

3.1 Issue ranking and ranking interpretation

Eighty percent of the 60 identified usability issues in the current study were rated as moderate significance or higher, with the most frequently occurring ratings being severe and moderate (Figure 7). Technical complexity ratings were distributed relatively equally across the ratings of minimal, moderate, and difficult. Seventeen percent of usability issues were rated as not being feasible to address. Seventy-five percent of the identified usability issues were rated as being able to be addressed with the existing project resources. Fifty percent of the identified usability issues were rated as being of high priority, requiring immediate resolution within the following 6-months of the project. No usability issues were classified as "not a priority."

Usability issues were organized and visually mapped on the basis of their significance, technical complexity, resource availability, and implementation priority ratings (Figure 8). Usability issues increase in significance from the bottom of the map to the top and increase in technical complexity from left to right. Usability issues would be prioritized from the top-left box, with issues represented in solid brown fill prioritized first. Of the 60 usability issues, 33% were rated as high priority, of notable significance to the user experience (moderate to critical), and technically feasible to resolve (minimal to difficult complexity with available resources). For example—usability issue 13 was identified as having a critical significance (top row) and minimal technical complexity (left-most column), with high implementation priority (brown fill) and available resources to address (solid fill)—therefore addressing this issue should be prioritized.

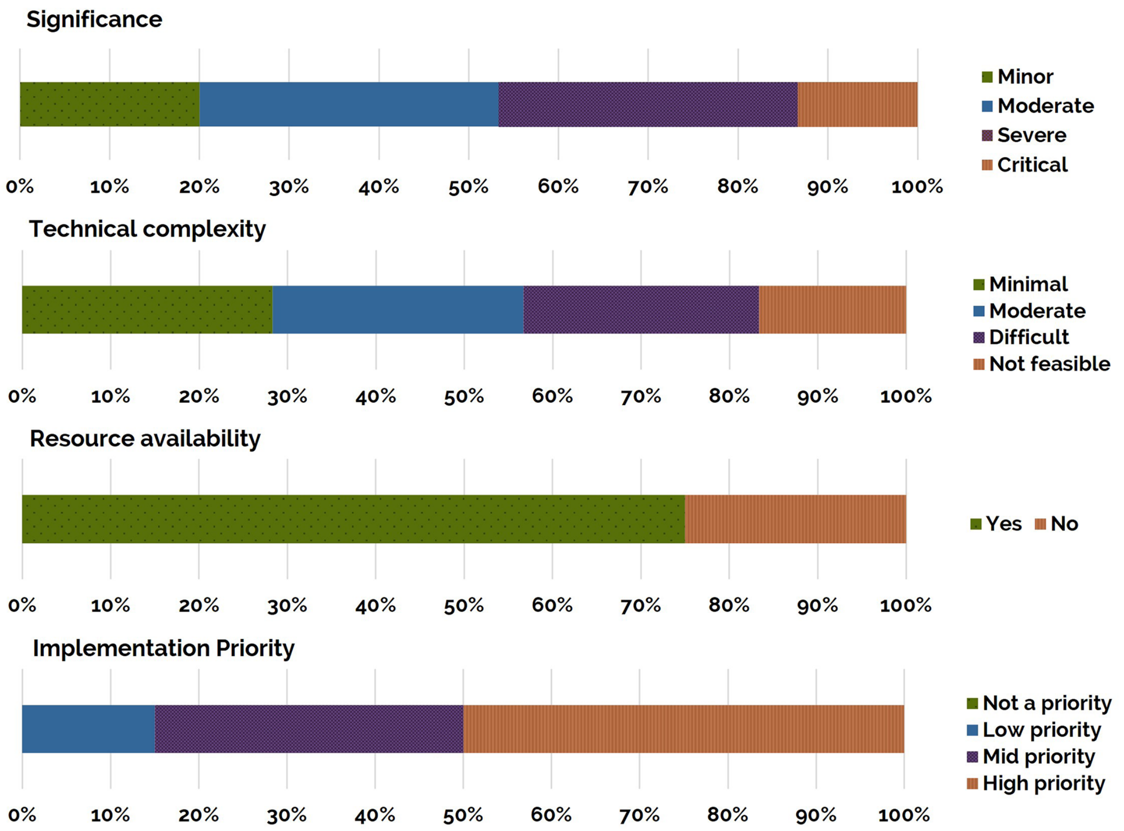
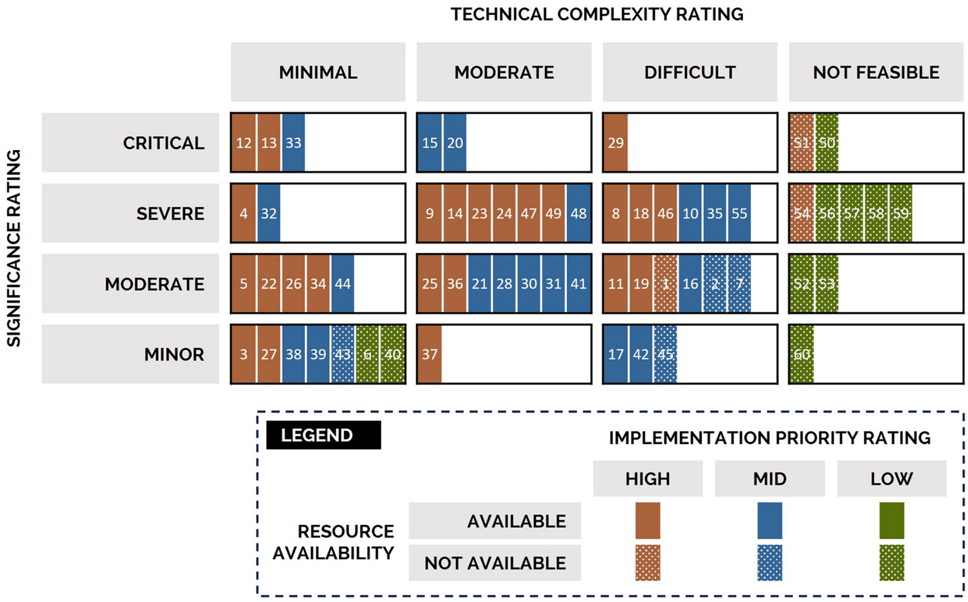


FIGURE 7
Ratings for the identified 60 usability issues: significance, technical complexity, resource availability and implementation priority (top to bottom). Each bar presents the percentage of the total number of issues identified at each rating. Rating descriptions are presented in Appendix 1.



TECHNICAL COMPLEXITY RATING

SIGNIFICANCE RATING	MINIMAL	MODERATE	DIFFICULT	NOT FEASIBLE
CRITICAL	12 13 33	15 20	29	51 50
SEVERE	4 32	9 14 23 24 47 49 48	8 18 46 10 35 55	54 56 57 58 59
MODERATE	5 22 26 34 44	25 36 21 28 30 31 41	11 19 1 16 2 7	52 53
MINOR	3 27 38 39 43 6 40	37	17 42 45	60

FIGURE 8
Mapping of usability issues according to their significance (rows), technical complexity (columns), resources (patterning), and implementation priority (color) ratings. Issue numbers are provided solely as indicators as specific issues are not of relevance here. Usability issues would be prioritized from the top-left box (critical significance, minimal technical complexity), with issues represented in solid brown fill (high implementation priority, resources available) prioritized first. No usability issues were classified as "not a priority.".

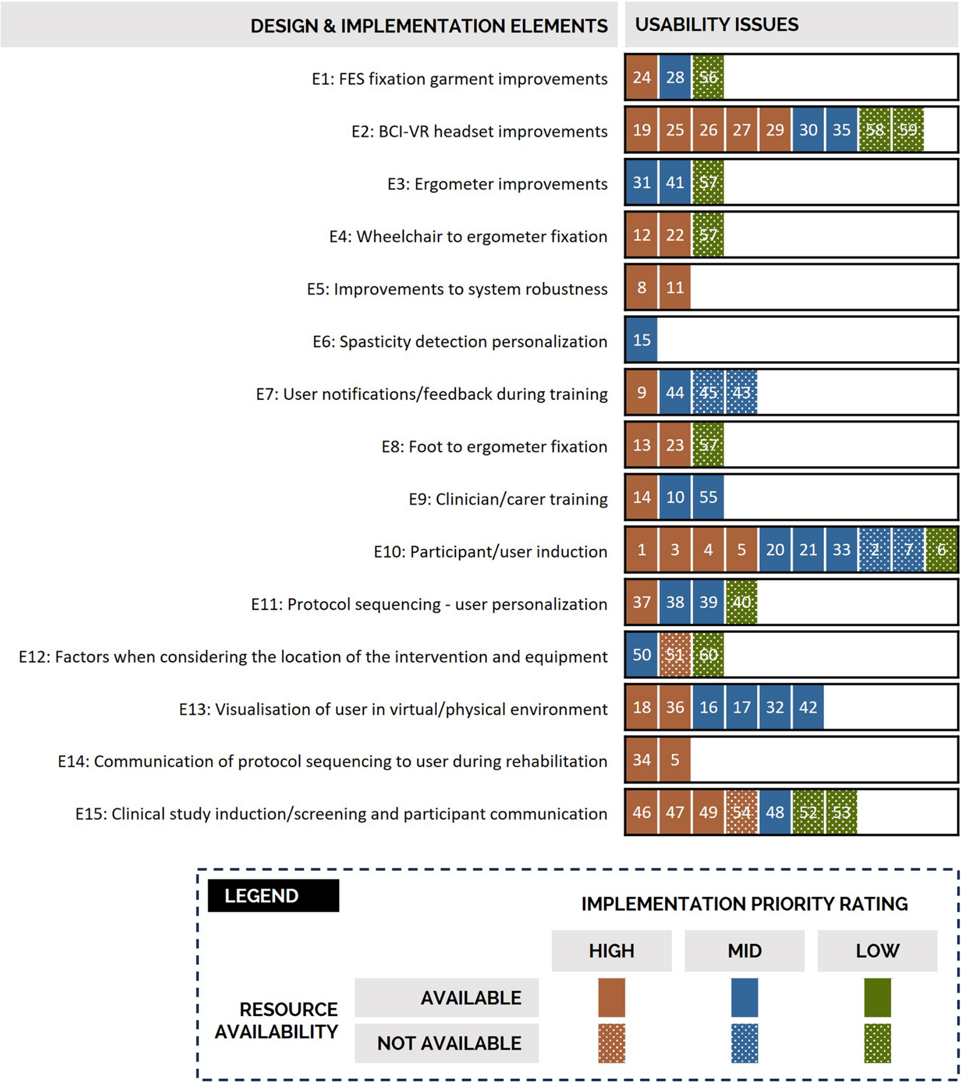


FIGURE 9
Grouping of the 60 usability issues into 15 design and implementation elements to support solution generation. Each issue has its associated implementation priority and resource availability indicated using the formatting indicated in the provided legend. For example, usability issues 24, 28 and 56 were identified as relating to the design and implementation element relating to functional electrical fixation garment improvements. Issue 24 was identified as high implementation priority, 28 as mid, and 56 as low. There were resources available within the project to address issues 24 and 28. FES = functional electrical stimulation; BCI = brain computer interface; VR = virtual reality.

3.2 Integrating usability issues into the product roadmap

The 60 usability issues were coded to the technology's corresponding sub-system or component and then aggregated into 15 design and implementation elements (Figure 9) to facilitate solution generation. Several issues related to more than one design or implementation element (e.g., issue 57 related to E3, E4, and E8). After completion of the breakout workshops and refinement of best candidate solutions, 21 tasks were raised within the technology's product. Of the 21 tasks, six were deemed to be technically feasible to address with currently available project resources (i.e., staff with appropriate expertise had access to required technologies and capacity to implement planned solutions). These six tasks were therefore actioned and integrated into the succeeding two technology iterations, the development and release of which ran on 3-monthly cycles. In parallel, development activities were initiated for an additional nine product roadmap tasks. These nine tasks had higher technical complexity and/or resources were only expected to become available to fully implement solutions in future development releases (i.e., staff with appropriate expertise were already engaged in previously planned development activities and/or implementing solutions to other roadmap tasks). The remaining six product roadmap tasks await resource availability, completion of predecessor tasks, and/or maturation of associated sub-systems prior to action and are therefore planned to be implemented using future project funding. For illustrative purposes, a worked example following the identification, prioritization, and resolution of issue 9 through two of the 21 tasks is provided below.

3.3 Worked example of issue 9

Usability issue 9 related to the potential for system interruptions to confuse users and was encountered by two out of the five individuals with a spinal cord injury during usability testing. This issue was rated to be of severe significance, highly impacting user comprehension and experience as participants identified misattributing system interruptions to their own actions (Figure 4, Significance Rating). While the operating clinician receives system state notifications via a graphical user interface, this information was not displayed to the user within the virtual reality environment. Absence of clear and timely information provided to the user about the cause of system interruptions was identified by the Design Team as contributing to user confusion. The issue was rated of moderate technical complexity to address, due to multiple system components that could cause changes in the functioning of the system (e.g., excessive negative torque being produced by the user during cycling beyond safety limits due to spasticity, or a electrode no longer in contact with the user's skin) (Figure 4, Technical Feasibility). There were deemed sufficient resources within the existing project to address the issue (i.e., staff with appropriate expertise had capacity), due to the potential of addressing the issue through a short-term solution (i.e., presenting real-time information to the user about the system being interrupted). On the basis of its significance and technical feasibility ratings, issue 9 was rated by the Steering Committee as having high implementation priority, requiring resolution within the next 6-months (Figure 4, Implementation Priority Rating).

The Design Team coded usability issue 9 as a system/protocol operation issue (Figure 6, Issue Coding), then grouped it under the "user notification/feedback during training" (E7) design element (Figure 6, Issue Grouping). Following solution ideation (Figure 6, Solution Ideation), two tasks were raised within the product roadmap (Figure 6, Solution Mapping and Tracking). Due to the severe significance rating of the underlying usability issue and associated high implementation priority rating, tasks were raised for immediate action.

The first task targeted improved visual system notifications for the user within the virtual reality environment. The notifications would be provided to the user during system interruption, e.g., in response to spasticity triggering the safety monitoring system (Figure 10). The first task scheduled for integration within the subsequent design iteration.

The second product roadmap task related to integrating sound notifications for the user. These sounds indicate not only the system status, but also session progress, providing additional context to users so they can better understand the source of interruptions and lessen confusion. The second task required modifications to interfacing sub-systems. Accordingly, the second task was scheduled for integration within a later design iteration.

4 Discussion

Usability testing can raise numerous and sometimes competing priorities that can be challenging for technical experts alone to

FIGURE 10
New system status notification implemented in response to usability testing. To reduce confusion to the users during potential system interruptions, the depicted notification will be provided to the user displayed via virtual reality during system interruptions.

manage. In this paper, we propose a collaborative method to prioritize user-identified issues, and subsequently integrate solutions to these issues into a device's product roadmap. We presented a case study of a novel system for neural recovery after spinal cord injury, where the project's Translation and Design Teams and Steering Committee iteratively worked on 60 issues previously identified by end-users.

Single-stakeholder approaches to evaluating usability may easily overlook the diverse perspectives of various relevant rehabilitation stakeholders, leading to an unbalanced assessment of a device. Collaboration between technical and non-technical stakeholders in the proposed usability evaluation method promotes consideration of objective and subjective user experiences, verification of pre-conceived expectations, reconciliation of competing design and implementation priorities, and transparency in decision-making. To promote collaboration with stakeholders, we applied a multi-phase method wherein three separate transdisciplinary groups applied their lived experience and expertise to collaboratively assign ratings to identified usability issues. The significance of usability issues was rated by translation experts, which was provided to design and development experts who rated technical feasibility, both of which were provided to external stakeholders to consider when rating the implementation priority of potential solutions. Significance and technical feasibility ratings were decided through consensus, which allowed for participating members' different experiences and expertise to be considered prior to a final rating being assigned. In contrast, due to practical issues related to the limited availability of the project's external stakeholders, each Steering Committee member provided an implementation priority rating independently and in consideration of their own experiences and expertise only. To reduce the subjectivity of the implementation priority ratings, tangible criteria relevant to the project for each rating were specified, e.g., a mid-priority implementation issue needs to be resolved within 6–9 months prior to the completion of the funded project, and the median rating across all Steering Committee members was assigned as the final implementation priority. This transdisciplinary approach engaged individuals in the fields of health, policy, engineering, design, and neuroscience, as well as individuals with a spinal cord injury. Although stakeholder engagement can be costly and time intensive, it was considered important to provide a broader perspective to the implementation priority of usability issues, that was less biased by existing priorities and demands within the project.

In our approach, the Translation Team considered the number of users who experienced each usability issue in conjunction with the proposed impact of the issue on a user (e.g., discomfort and/or inability to use the system) in assigning significance ratings. The implementation priority of resolving each issue was evaluated by the Steering Committee using this information in the context of the technical complexity of resolving the issues and resources available within the project. Issue ratings were visually represented to guide the implementation of tasks to resolve issues within the technology design process. Previously, data-driven approaches have been used to objectively quantify the significance or severity of issues. Abrantes and colleagues (18) propose a classification method to organize issues into four quadrants, where assigning a quadrant is based on an interaction between the criticality of the task being completed and relevancy of the problem. However, as the criticality rating is based on task completion, rather than the impact on the user, it can be argued that this method provides a limited understanding of user experience. Hassenzahl (30) explored a problem-handling time metric approach to severity estimates, in which the amount of time users spent dealing with interaction issues directly indicated the severity of the problem, regardless of frequency. In this data-driven approach the experiential elements of usability are ignored, e.g., an issue that creates a high level of discomfort over a smaller period may be prioritized lower than an issue with a moderate level of discomfort over a longer period. Sharon and colleagues (31) presented a 3-level scale of issue severity, influenced by the frequency of the issue e.g., if an issue occurs in more than 10 users it is automatically classified as a high-severity problem regardless of the significance of its impact on their individual experiences. However, this approach limits the understanding of the significance of issues experienced by single users ($n = 1$), which by this system would be considered as "irrelevant" or of low significance (14). Considering the small number of participants commonly recruited for usability testing in academic research, we propose that frequencies alone should not be used to prioritize or dismiss usability issues. Rather, we suggest infrequently occurring issues serve as a starting point for further investigation of the usability, utility, and acceptability of the device across a wider user group of representative users.

Usability issues integrated into the product roadmap in our case study were influenced by implementation priorities identified by the external stakeholders that were the Steering Committee, as well as factors specific to the Design Team's workflow. For example, opportunistic resource availability (e.g., small research projects, internships, funding opportunities) may influence the order in which identified usability issues are able to be addressed, e.g., funding becomes available for a small research project that could address an issue with a low implementation priority. Resource-related factors, including the availability of staff to work on multiple usability issues relating to a particular sub-system and/or the number and complexity of existing tasks identified for priority development, also influences the order in which priorities can be addressed. Additionally, some of the issues raised during the usability testing were identified during parallel pilot testing of the technical aspects of the prototype and addressed prior to the end of the rating process. In these instances, implementation priority ratings served to confirm assumptions held by project designers and provided valuable insight into the importance of these tasks. Mapping and tracking of solutions were led by the projects' Design Team. In co-design, all stakeholders engaged in a project should be actively involved in and share decision-making throughout development (2–4). However, in practicality, not all stakeholder groups are involved in all elements of day-to-day decision making. It is therefore essential that transparency in, and communication of, the decision-making process is maintained (e.g., through the mapping of tasks in a product roadmap) to ensure that the final solution reflects the opinions of multiple stakeholder groups.

4.1 Limitations and future directions

There are several practical considerations or limitations with our approach that warrant notice. Separate to usability session participants, two individuals with lived experience of spinal cord injury were involved in assigning the significance and implementation priority ratings (one individual per rating), and one individual with lived experience of spinal cord injury was involved in solution generation workshops. We note that inviting the original participants of the usability trial to participate in the significance and implementation priority rating sessions alongside project team members would have increased the voice of individuals with lived experience of spinal cord injury and, therefore, enhanced the robustness of the overall process. Consultation can be a timely process, dependent on the availability of stakeholders outside of the project or the organization, therefore in some instances, usability issues were identified in parallel by chance and addressed prior to ratings being made available. Approaches like instant data analysis, in which usability sessions are held on a single day and followed by a single brainstorming session in which as many issues remembered are recorded and mapped, may help to expedite the process (14, 15). Issues were categorized twice in our approach, once to indicate the associated facet of usability (in Phase 1), and once according to the design and implementation elements (in Phase 3). A more collaborative approach from the onset between the Design and Translation Teams in the organization and categorization of the data may have improved the efficiency of this analysis process. To further enhance the robustness of the methods detailed in this study, we encourage future work that uses collaborative approaches to streamline the organization and categorization of data (i.e., to ensure that initial data categorization is able to facilitate both issue rating and solution generation) and invites usability trial participants with lived experience of disability to participate in rating sessions alongside project team members (i.e., in a way that means power is shared during decision-making).

5 Conclusion

In this study, we introduced an approach for the prioritization of usability issues highlighted by end-users during the evaluation of a novel rehabilitation technology. The distinguishing strength of this approach is its embrace of transdisciplinary collaboration, amplified by the independent prioritization executed by an external stakeholder group, enriched by a spectrum of pertinent experiences and expertise in the field of technology for rehabilitation. This approach embeds co-production principles such as including all perspectives and skills, respecting and valuing the knowledge of all those working together on the research, and sharing power. We have provided a detailed example to elucidate how significance, technical feasibility, and implementation priority ratings can be practically utilized to transparently inform future design iterations. We also discuss recommendations for how the described usability issue rating method could be improved for efficiency and application in other testing environments.

Data availability statement

The datasets presented in this article are not readily available as the technology discussed is under active development and full data disclosure would violate intellectual property agreements. Requests for access to redacted transcripts of interviews should be directed to KC, k.clanchy@griffith.edu.au. Requests to access the datasets should be directed to KC, k.clanchy@griffith.edu.au.

Ethics statement

The studies involving humans were approved by Griffith University Human Research Ethics Committee (HREC), reference number 2019/994. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

KC: Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Visualization, Writing – original draft, Writing – review & editing. JM: Conceptualization, Data curation, Formal Analysis, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing. KM: Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Visualization, Writing – original draft, Writing – review & editing. EJ: Conceptualization, Data curation, Investigation, Methodology, Project administration, Supervision, Visualization, Writing – original draft, Writing – review & editing. EK: Conceptualization, Funding acquisition, Visualization, Writing – original draft, Writing – review & editing. DL: Conceptualization, Funding acquisition, Resources, Writing – review & editing. DP: Conceptualization, Funding acquisition, Resources, Writing – review & editing. CP: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Visualization, Writing – original draft, Writing – review & editing. CS: Conceptualization, Formal Analysis, Investigation, Methodology, Project administration, Supervision, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

Publisher's note

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Appendix 1: Rating scales applied

Rating		Scale
Significance rating		Minor = minor issue experienced by participant when using the system Moderate = moderate delay, frustration, or discomfort experienced by participant when using the system Severe = significant delay, frustration, or discomfort experienced by participant when using the system Critical = participant was unable to use the system
Technical feasibility	Technical complexity	Minimal = resolving the issue is easy from a technical perspective Moderate = resolving the issue is moderately technically complex Difficult = resolving the issue is difficult from a technical perspective Not feasible = resolving the issue is not technically feasible
	Resource availability	Yes = the issue can be resolved with the existing project resources (time, equipment, expertise, financial costs) No = the issue cannot be resolved with the existing project resources (time, equipment, expertise, financial costs)
Implementation priority rating		Not a priority = resolving issue is unnecessary and/or unfeasible Low priority = issue to be resolved over the long-term i.e., after the next 9 months and using future project funding Mid priority = issue to be resolved in the short- to mid-term i.e., in the next 6–9 months and before completion of current project funding High priority = issue to be resolved immediately or in the short-term i.e., in the next 6 months

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Shining a light on the road towards conducting principle-based co-production research in rehabilitation

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Moving from participatory approaches incorporating co-design to co-production in health research involves a commitment to full engagement and partnership with people with lived experience through all stages of the research process—start to finish. However, despite the increased enthusiasm and proliferation of research that involves co-production, practice remains challenging, due in part to the lack of consensus on what constitutes co-production, a lack of guidance about the practical steps of applying this approach in respect to diverse research methods from multiple paradigms, and structural barriers within academia research landscape. To navigate the challenges in conducting co-produced research, it has been recommended that attention be paid to focusing and operationalising the underpinning principles and aspirations of co-production research, to aid translation into practice. In this article, we describe some fundamental principles essential to conducting co-production research (sharing power, relational resilience, and adopting a learning mindset) and provide tangible, practical strategies, and processes to engage these values. In doing so, we hope to support rehabilitation researchers who wish to engage in co-production to foster a more equitable, ethical, and impactful collaboration with people with lived experience and those involved in their circle of care.

KEYWORDS

co-production research, lived experience research, research partnership(s), epistemic justice, capacity building, rehabilitation research design

1 Introduction

The idea of participatory research, where people with lived experience and rehabilitation researchers partner together in the planning, design, conduct, dissemination and implementation of research, has attracted increasing attention and enthusiasm in recent decades (1–3). The push for participation, in part, is due to increasing recognition that partnering with people with lived experience increases the relevance of research priorities and outcomes (4, 5) and raises the quality of interpretation and knowledge translation (6) as it is more reflective of lived reality and can bridge the gap between research and practice (4, 7, 8).

There are many participatory approaches with concepts and terms often used interchangeably (9, 10). This has led to what Williams et al. (2) termed *cobliquity*, which refers to the emergence of "a plethora of "co" words, promoting a conflation of meanings and practices from different collaborative traditions" (p. 2). Indeed, each participatory approach has a distinct history, concepts, and commitments to power-sharing with people with lived experience (11–13). Two approaches that are commonly used are co-design and co-production. While there is no consensus regarding use of these terms (14), co-design often refers to collaborative approaches with design elements, and has its origins in Scandinavian "co-operative" or "participatory" design with end users of products, services, and workplaces (15, 16). Co-design involves partnership with people with lived experience in one or more stages of the research process (17)—although a substantive approach may encompass all stages (15). The increasing popularity of co-design no doubt reflects a renewed focus on person-centred and collaborative models of healthcare provision and a greater involvement of patients and community members in health research (18). Further, changes in the research management landscape (such as requirements of ethics committees and health research funding bodies) mean that there is now a greater focus on partnerships (8).

Co-production, on the other hand, which originated in US social care and justice movements (19) refers to a collaborative approach that centres reflective dialogue (15, 20). There are growing demands from consumer and disability movements for co-production research. Co-production has often been described as the "gold standard" for participatory research (21), and motivated by an "egalitarian imperative" (2). Co-production has strong commitments to collaboration and power-sharing throughout all stages of the research process (20), and can also involve development of research agendas with affected communities (15), establishing health policy (22) and translating evidence into action (11). The push for co-production research has largely come out of recognition of human rights violations against people with lived experience (23, 24) and a central desire to redistribute power in the social relations of research to promote epistemic and health justice (25–27).

Despite the increasing attention on, and proliferation of co-production research, practice remains challenging (28), which is in part due to the lack of consensus on what constitutes co-production in the context of health research (2, 9). Challenges include a lack of guidance in relation to the practical steps of applying this approach across diverse research methods from multiple paradigms (1, 8), and structural barriers within academia and funding landscapes, which are often conflicting with the practice of co-production research (27, 28). To navigate the challenges in conducting co-produced research, it has been recommended that attention be paid to advocating for and operationalising the values, principles, and aspirations of co-production to aid translation into practice with lived experience communities—not as a linear approach but rather as an ethos that shapes practice (2, 9, 28). As such, co-production has been described as a principles-based approach, and a process which can draw on multiple methods from multiple paradigms (1, 8, 26).

To this end, numerous efforts have been made to articulate and classify the underlying principles and values conducive to co-production research [for example, see Hickey et al. (29) and Gainforth et al. (4)]. Notable commonalties amongst these principles include the redistribution and sharing of power—where the research is jointly owned and people work together to achieve co-determined outcomes (4, 29, 30). This is accompanied by relationship building and maintenance to enable contribution with power sharing (1, 3, 27). The adoption of a learning mindset—whereby team members embrace different perspectives and build capability through undertaking an iterative approach and being open to adjustments based on ongoing reciprocal feedback, is also important (28, 31, 32).

Although this broad conceptualisation of practice can help guide researchers, they might nonetheless be experienced as rather abstract and hard to operationalise in practice. While some existing resources suggest recommendations on how to conduct co-production research [for example, see Hickey et al. (29), McKercher (33) and Bellingham (15)], there remains a need for guidance regarding how researchers might navigate the everyday challenges of co-production research. In the following section, we, as a group of researchers engaged in co-production research from lived experience and "conventional" (non-lived experience) positions, present some common challenges to conducting co-production research and some pragmatic strategies we have used to address these (See Table 1).

1.1 Navigating power dynamics

1.1.1 Challenge

Breaking down power imbalance and structural inequities for power sharing.

Plamondon et al. (30) argue that power is the overarching and essential problem of research co-production. Not only is the research process (involving the systematic nature of knowledge enquiry) founded on human relationships, "power and positionalities shape who and what is seen, privileged, and legitimized as worthy of research and implementation attention and resources" (p. 37). People with lived experience have historically been excluded and invalidated in research (28, 34). The influence of research context also matters (2), and traditionally, power has resided with conventional researchers due to structural inequalities and embedded hierarchies within research institutions and structures, such as existing in universities and research funding systems, which often reflect society more broadly and structural inequalities (28). However, reflecting on power relationships is becoming more common and receiving more attention in the literature, and there are now several ways to acknowledge and work towards mitigating power inequities and practicing more equitable co-production research (2, 34).

TABLE 1 Overview of principles, challenges, strategies, and recommended readings.

Principles	Challenges	Strategies	Recommended reading
1. Navigating power dynamics	• Power and positionalities shape knowledge creation and knowledge value. • People with lived experience have historically been excluded and invalidated in research.	• Be deliberately reflective and attentive to status throughout the research lifecycle. • Have honest, high-quality conversations between those with lived experience and researchers. • Establishing a democratic governance framework. • Building flexibility into timelines, support those with lived experienced to take the lead on projects or project components, set clear meeting agendas. • Include adequate representation and remuneration of people with lived experience. • Building research skillsets and/or developing research career pathways for those with lived experience.	• Plamondon et al. (30) • Staniszewska et al. (34) • Bell and Pahl (3) • Flinders et al. (7) • Bourke et al. (35) • Williams et al. (2)
2. Building relational resilience	• Democratic rationales for co-production research require conventional researchers to employ more equal relations than they may have been accustomed to. • Traditional academic and research funding practice can lack the flexibility required to build and maintain meaningful relationships.	• Invest time with community partners even before initiating the research. • Adopting an approach of "generous hospitality" to ensures that people with lived experience feel welcome. • Identify joint priorities, as well as support dialogue around appropriate and acceptable research questions, methodologies, timelines, roles, governance structures, and dissemination strategies. • Accessible and appropriate ways for people to digest and contribute information. • Ensure venues, information mediums and communication and timeframes are accessible.	• River et al. (27) • McKercher (33) • Cooke et al. (36) • Bellingham et al. (15) • Daya et al. (37) • Happell et al. (21) • Middleton et al. (17)
3. Adopting a learning mindset	• Real world practicalities (e.g., complex power relations, competing or conflicting intentions, lack of organisational support, and expectations and priorities which can frustrate the research process). • Unexpected barriers and challenges (e.g., contacting those lived experience, navigating the sharing of decision making, experiencing instances of not knowing what to do next).	• Learn through doing—be as flexible and adaptable as possible. • Embrace and practice dialogue (act of listening, sharing, and acknowledging others point of view) and iteration (being open to adjustments based on ongoing reciprocal feedback, and seeing and valuing different perspectives).Make time to reflect on how the group is working and whether initial ideas about communication and relationships are being maintained and/or need development.	• Langley et al. (11, 31, 32) • Hickey et al. (29) • McKercher (33) • Gainforth et al. (4) • Hoekstra et al. (5) • Sibley et al. (38)

1.1.2 Strategies

There are a variety of ways in which researchers can promote parity in co-production teams. At a foundational level, conventional researchers (as the traditional power holders) need to be deliberately reflective and attentive to their status throughout the research lifecycle and lived experience perspectives need to be elevated. As McKercher (33) states "elevating the voices and contributions of people with lived experience means challenging power differences. Including what is considered evidence, who gets heard, who gets to decide, and who is in the room". Staniszewska et al. (34) argues that honest, high quality conversations between those with lived experience and researchers that take account of how power works in research can serve to create a more fertile and kinder context for co-production research. At a practical level, efforts to address power inequities may include establishing an open governance framework, that clearly articulates the decision-making process and how disagreements will be navigated. It also includes building flexibility into timelines, supporting those with lived experienced to take the lead on projects or project components, setting clear meeting agendas and deciding on what time should be spent on particular topics/activities (36). Two further important equity efforts are to include adequate numbers of people with lived experience and remuneration for lived experience (39), and ensuring that co-production projects build skillsets and capacity in all members of the team (e.g., all members are trained in co-production research principles and practices), which may take a longer commitment beyond the life of the project (35, 40).

1.2 Building relational resilience

1.2.1 Challenge

Being able to invest the time, effort and resources necessary to build trust and understanding of the needs of people with the lived experience.

Rycroft-Malone et al. (1) suggest authentic co-production requires a "sustained investment in building and maintaining meaningful relationships" (p. 291). As such, the building of trust and a shared vision for a research project with people with the lived experience requires more time, effort and resources compared to conventional research methods (27). This investment in building meaningful relationships can be challenging, with democratic rationales for co-production research requiring conventional researchers to employ more equal relations than they may have been accustomed to (2). In addition, traditional academic and research funding practice can lack the flexibility required to build and maintain meaningful relationships (4), which may make it difficult to estimate in funding requests or lead to costs stretching beyond a proposed budget, and may also be at odds with the tight timeframes imposed by funders and universities (4, 27). However, while challenging, investing time, energy and resources in building relationships and understanding motivations and intentions for the project, is nonetheless necessary for establishing authentic partnerships (27), and for co-production research to ultimately flourish or fail (1).

1.2.2 Strategies

Building trusting relationships is a key strategy of co-production teams. River et al. (27) found that relational connection in research teams is essential to enabling sharing of lived expertise, which is not only conceptual, but also as Bell and Pahl (3) have argued, tacit, embodied, personal and emotional. Building relationships often requires researchers to invest time with community partners even before initiating the research. When preparing, taking the opportunity to discuss with affected communities who should be involved and what the focus of the research might be is useful for ensuring research relevance and supporting later implementation efforts (15). Once established, taking time and paying attention to relationships can also support "relational resilience" to navigate conflict and team disagreement when and if it arises (27). McKercher (33) suggests adopting an approach of "generous hospitality" to ensures that people with lived experience feel welcome and that their hopefulness for equity and change is "cared for". McKercher (33) notes that basics are vital, including ensuring that we know people's names, offering food and drinks, and welcoming everyone each time. Cooke et al. (36) also emphasises that in relationships, researchers be nimble, honest, and reciprocal—endeavouring to listen and offer perspectives to the dialogue.

Through building relationships, conventional researchers, who are motivated by values of equity, can begin to develop an understanding of the motivation of partners with lived experience (a process inevitably related to power, see below). Bellingham et al. (15) also note that conventional researchers may hold "unexamined and unarticulated intentions that are at odds with the intentions of lived experience researchers". While conventional researchers may see lived experience input as an "add-on", lived experience researchers may view it as promoting epistemic justice, which is central to equity and social change (41). Early articulations of intentions and motivations for a project can help co-production teams to identify joint priorities, as well as support dialogue around appropriate and acceptable research questions, methodologies, timelines, roles, governance structures, and dissemination strategies (15). In these discussions, teams must not only value diverse forms of expertise, but also welcome divergent views as disruptive, and potentially tense dialogue, which is indeed a strength of co-production as it encourages innovation and helps to ensure relevance and resonance to lived experience communities (37, 42). Having a process for resolving disputes at the outset can potentially help enable and depersonalise disruptive and tense dialogue.

Facilitating effective communication is essential and requires several pragmatic considerations. For example, thinking carefully about how to optimally share, use, and capture information (32), offering appropriate ways and mediums for people to digest and contribute. Giving consideration to the meeting location (15) is important for making engagement opportunities accessible and inclusive for those of the lived experience to participate fully. Further considerations (in a rehabilitation context) include how various biopsychosocial consequences of impairments might impact on the associated environmental factors and practice of relationship building, timeframes and accessibility (4). Building relationships can be of value not just for one research project but for research efforts over time. Furthermore, building relationships can be critical in brokering greater participant recruitment, building research skillsets and/or developing research career pathways for those with lived experience (5, 35).

1.3 Adopting a learning mindset

1.3.1 Challenge

Co-production research ideals are often challenged by real world practicalities.

The transformative promise of authentic co-production research (in the research space, and through the renewal of wider scientific democracy) is often stymied by complex power relations, competing or conflicting intentions, lack of organisational support, and expectations and priorities, which can frustrate the research process (7). Many researchers engaging in co-production acknowledge such difficulties and admit that conducting "perfect" co-production research is perhaps a quixotic quest (28).

1.3.2 Strategies

Adopting a learning mindset is a key consideration (33). As Langley et al. (32) suggest, "co-production research is not a technique you apply rightly or wrongly, but a journey of learning, and it is not a journey you make alone" (p. 112). So much about co-production can be learnt through doing. Because co-production does not have a prescribed method nor a checklist, research can employ a flexible and adaptable approach. Practical experience can be gleaned through starting what is possible for often limited resources and expertise (15). When doing so, Langley et al. (32) suggest that two important processes intractably linked to the core values of co-production research include dialogue and iteration. Dialogue refers to the interaction and act of listening, sharing, and acknowledging others point of view. This includes acknowledgement and engagement with lived expertise of lived experience researchers, as well as acknowledgement and engagement with "learned" expertise of conventional researchers. Three qualities which can greatly benefit listening and acknowledgement of diverse perspectives include *flexibility, adaptability, and humility*. Iteration refers to the applied use of such interaction and incorporation of feedback with ongoing learning, which results from step change.

Embracing an iterative approach, being open to adjustments based on ongoing reciprocal feedback, and seeing and valuing different perspectives is essential (5, 38). For example, when reflecting on their experiences of bringing co-production principles into practice, Farr et al. (28) recommend that making time to reflect on how the group is working and whether initial ideas about communication and relationships are being maintained and/or need development is vital to ensuring that people are being heard and their needs are addressed. Furthermore, seeing and valuing different perspectives goes both ways between those with lived experience and conventional researchers (5). People with lived experience might need to be adaptable. This can be a potentially awkward part of the co-production process but very important to realise the two-way nature of the co-production research (38).

2 Discussion

With increasing calls for epistemic and health justice, the practicing of authentic, sustainable co-production which focuses on equality and reciprocity, will likely become the "new normal" and commonplace in health research (10, 43). However, as many researchers have reported, co-production research can be challenging in practice (15, 22, 34). In order to avoid tokenism, and conduct of co-production "in name if not always in deed" (1) (p. 290), attention to the values and principles of co-production research is required, but also strategies to manage common challenges related to power dynamics, relationships, and real-world contexts.

It must also be acknowledged that the practice of co-production research takes place within a vast research ecosystem, which does not traditionally facilitate the egalitarian nature of co-produced research (1, 2). The practice of co-production research is often portrayed as being inherently more difficult, time consuming and resource intensive than conventional research [for example, see Oliver (42)]. However, many now argue that such risks and challenges of co-production research are not the result of "bad practice" *per se* (2), but instead result from systematic barriers within the research landscape. Common barriers may include the embedded hierarchies and structural inequalities in universities, culture of public service institutions and research funding systems, inflexible funding timelines, and valuing of non-typical research outputs and metrics) (2, 7, 28, 44).

However, there is a great desire to transform the practice, culture, and structures of the research ecosystem to be more encompassing of authentic co-production research (28, 34). Increasing discussion is challenging multiple areas across the research ecosystem, including how funders can be more enabling of co-production research (1), how the public, researchers and policymakers can work better together to co-produce and implement evidence-based policy (22), and how co-produced models of research commissioning within public health can improve the setting of research agendas (44). Furthermore, there is a current lack of practical co-production research evaluation frameworks. To address this gap there are increasing and concerted efforts being made to develop, test, and refine evaluation frameworks. For example, the Research Quality Plus for Co-Production (RQ + 4 Co-Pro) Framework (45), and for co-design, the Preferred Components for Co-design in Research (PRECISE) guideline (46). Having such approaches which aim to help evaluating the quality of participatory research can help both co-producers learn and improve their practice, and provide a greater methodological impetus for co-production research projects to be more widely accepted by funders (47).

While our discussion has mainly focused on co-production research practice, there is growing consensus that co-produced research is a critical mechanism to improve research translation and benefit clinical practice (4, 48, 49). To date, participatory research within rehabilitation settings has reported successful achievement of focused clinical-level outcomes, such as having lived experience involvement in clinical service and technology development (50, 51). The challenge now for the rehabilitation research community is to engage in genuine epistemic, or knowledge, justice—founded on (but not limited to) the principles of power sharing, relationship building and adaptability (2, 4, 52). Epistemic justice is vital and necessary in rehabilitation research, not only to improve the translation of lived experience knowledge to practice, but because partnership with people with lived experience of disability in the production of knowledge actively commits to the rights of disabled people (53), and makes real the demand for "nothing about us without us" in the production of rehabilitation research (4, 54).

3 Conclusion

Creating more optimal conditions for co-production research will inevitably require a more equitable approach to research, which challenges our current systems of research production. The multitude of contexts and stakeholders involved throughout the entire research ecosystem will inevitably require creative approaches to co-production research (31). Part of this journey requires researchers to understand some fundamental principles essential to conducting co-production research, and have access to tangible, practical strategies, and processes to properly engage these principles. In this paper, we have offered a few entry-point strategies to support researchers with these common challenges, including strategies to navigate power dynamics via intentional dialogue and clarity for decision-making processes; strategies to build relational resilience in research teams via attention to relationships, intentions, and motivations; and moving beyond perfection to adopting a learning mindset. While by no means an exhaustive list, we hope that rehabilitation researchers who wish to practice co-production research consider these strategies, which aim to foster a more equitable, ethical, and impactful collaboration with rehabilitation communities.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Author contributions

JB: Writing – review & editing, Writing – original draft, Conceptualization. PB: Writing – review & editing, Conceptualization. JR: Writing – review & editing, Conceptualization. KS: Writing – review & editing, Conceptualization. MA: Writing – review & editing, Conceptualization. JM: Writing – review & editing, Conceptualization.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Enablers and barriers to implementing an interdisciplinary experiential learning program for university students in a Canadian rehabilitation centre

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Objective: This qualitative study aims to identify a comprehensive set of enablers and barriers to implementing an interdisciplinary experiential learning program for university students at a Canadian rehabilitation centre.
Methods: A researcher conducted one-on-one semi-structured interviews with individuals from four key stakeholder groups (i.e., rehabilitation centre leadership, clinicians, university clinical coordinators, and health and rehabilitation students). Interviews and data analysis followed the Theoretical Domains Framework (TDF), which is designed to identify possible cognitive, affective, social, and environmental influences on program implementation. Interviews were transcribed verbatim, and two researchers coded data independently to identify the major themes of enablers and barriers to implementing an interdisciplinary experiential learning approach to rehabilitation care.
Results: From a total of 12 interviews, domains of the TDF were identified to represent overarching themes, which were (1) enablers (i.e., reinforcement, beliefs and consequences, optimism, professional identity, knowledge, and skills), (2) barriers (i.e., environment/resources and beliefs and capabilities), and (3) program development (i.e., goals and evaluation that was not previously a TDF domain). A list of recommendations for implementing an interdisciplinary experiential learning program was created that represented qualitative data from each stakeholder group.
Conclusion: This study provides insight into the potential enablers and barriers to developing an interdisciplinary experiential learning program for university students within rehabilitation centres. This type of program could enhance educational curriculums, student and clinical experiences, and patient outcomes. In this study, the findings inform recommendations for developing an interdisciplinary program in teaching hospitals and explore their potential impact. Future research and pilot studies must be conducted to fully understand the effects of implementing an interdisciplinary experiential learning approach within rehabilitation centres.

KEYWORDS

interdisciplinary, experiential learning, rehabilitation, program development, implementation

1 Introduction

Teamwork is a key component in rehabilitation centres and as having several disciplines collaboratively working together provides optimal patient care, successful interdisciplinary care is crucial to employ. There are various professions (e.g., physicians, nurses, occupational therapists, physiotherapists) that must work together, and interdisciplinary care can foster better communication and a collaborative work environment (1, 2). Interdisciplinary care differs from other models as team members are more interactive and interconnected rather than working in parallel (3). By having more individuals work collaboratively and provide different perspectives, interdisciplinary teamwork has been shown to improve clinical outcomes and enhance patient care (2, 3).

Alongside interdisciplinary care, experiential learning is another concept that would be beneficial to embed within rehabilitation practices. In this context, experiential learning is a way to introduce students to a more practical and hands-on experience and be able to engage in a clinical setting that is different from the typical class setting (4). Embedding both together and employing an interdisciplinary experiential learning approach will be especially beneficial to involving students from various backgrounds to assist clinical professionals and enhance rehabilitation care. Previous research shows that students who are engaged in both interprofessional learning courses and hands-on experience in a clinical setting have better outcomes in terms of knowledge, confidence, attitudes, and preparation (5, 6). From a student perspective, there are several benefits to engaging in experiential learning opportunities as they can work with other individuals and professionals who differ in background and knowledge (7). There have been programs across Canada that have provided experiential learning opportunities to students and found positive effects (8). Experiential learning is a key component of training for rehabilitation students across Canada; however, currently, there is often no focus on integrating an interdisciplinary approach to the program structure. To combat this limitation, a new interdisciplinary experiential learning program is being developed to ensure the integration of students from various disciplines.

Students gain a deeper appreciation for working in an interdisciplinary manner when exposed to that environment early in their education, which can help inform their future decisions (9). Interdisciplinary experiential learning allows students to appreciate the clinical perspectives of various healthcare professionals/disciplines and the impact that these professionals can have on patients and their families (3, 10). A pilot study conducted by Pechak and colleagues found that rehabilitation students [i.e., occupational therapist (OT), physiotherapist (PT), and speech and language pathologist (SLP)] felt the interdisciplinary course afforded them the opportunity for self-discovery, enhanced collaboration and satisfaction, and a chance to explore outside their comfort zone (11).

Previous research has explored various perspectives regarding interdisciplinary experiential learning from the student and supervisor/advisor perspectives (7, 12); however, these programs involve more than just students and supervisors as the opinions of hospital administrators and university coordinators should also be taken into account to optimally implement an interdisciplinary experiential learning program. One way to obtain this information is by using a framework that focuses on both implementation science and behaviour change from multiple perspectives. The Theoretical Domains Framework (TDF) focuses on those two aspects and can be used in several disciplines to help implement various interventions within healthcare, clinical practices, research, and more (13). For example, one previous study used the TDF to identify teachers' regarded barriers and facilitators to a mandated physical activity policy within a Canadian elementary school (14). This work found that using the TDF aided in understanding and improving future interventions and behaviour change techniques to help with implementation. Since developing and maintaining an interdisciplinary experiential learning program involves and relies on several fields and personnel working together (e.g., healthcare professionals, leaders, and administrators), examining behaviour change is important to successful implementation (15). The TDF combines both psychological and organizational theories and evidence-based recommendations to target specific behaviours that will lead to sustainable changes to support the intervention (16, 17).

This study aims to inform program development by interviewing key stakeholders about the implementation of an interdisciplinary experiential learning program informed by the TDF model. Understanding the various enablers and barriers to implementing this program can help spread awareness and support developing successful interdisciplinary experiential learning initiatives for university students in rehabilitation centres.

2 Methods

This qualitative study follows a phenomenological approach and was approved by the Western University Health Science Research Ethics Board (HSREB) in accordance with the Declaration of Helsinki. Informed consent was obtained from all participants prior to beginning the interviews.

2.1 Participants

For this study, members from four key stakeholder groups were interviewed: rehabilitation centre leaders, clinicians, university clinical coordinators, and students from various health and rehabilitation disciplines. Rehabilitation centre leaders oversee and coordinate the programs at the rehabilitation centre. Clinicians are supervisors of students from different health disciplines (e.g., physical therapists, physicians, and nurses). University clinical coordinators work within the university and are responsible for student organization and ensuring the program fits educational curricula. Students are from several health and rehabilitation areas who have taken part in experiential learning. Purposive sampling was used, where members of the research team identified potential participants.

2.2 Materials

The semi-structured interview guide was formatted to be one-on-one with open-ended questions and was developed by the research team with backgrounds in health science, rehabilitation science, and psychology based on the Theoretical Domains Framework (see Table 1). The Theoretical Domains Framework

TABLE 1 Original and adapted descriptions for the relevant domains used from the theoretical domains framework (13).

TDF domain	Original TDF descriptions	Adapted TDF description
Knowledge	An awareness of the existence of something	Anything that involves gaining more knowledge of interdisciplinary care
Skills	An ability of proficiency acquired through practice	Desirable skills of incoming students
Environment Context and Resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour	Structural or organizational circumstances that may help or hinder the implementation of an interdisciplinary experiential learning program
Social/Professional Role and Identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting	Aligning values of an interdisciplinary experiential learning program and one's personal or professional values
Beliefs and Capabilities	Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use	Ability to engage and be involved in an interdisciplinary experiential learning program
Optimism	The confidence that things will happen for the best or that desired goals will be attained	Confidence in the program's development and/or its values and goals
Goals	Mental representations of outcomes or end states that an individual wants to achieve	Ideas or suggestions made that would help achieve and support the desired outcomes of the program
Beliefs and consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation	Opinions or thoughts on what outcomes could occur from this initiative
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus	Circumstances or individual capabilities that help support/hinder the startup of the program (e.g., motivation and incentives)
Evaluation[a]	NA	Methods for measuring the success and progress of this program

[a] Not an original domain from the TDF.

aims to provide guidance on successful implementation and is designed to identify various influences on behaviour (e.g., cognitive, affective, social, and environmental) that could impact program implementation (13). By using a semi-structured interview, the participants were able to share relevant details to the study goal while also providing additional information that they felt was relevant to the study.

2.3 Procedures

2.3.1 Data collection

All participants provided informed consent prior to taking part in the interview. Interviews happened either in person ($n = 2$) or through Microsoft Teams ($n = 10$) by a researcher with background knowledge in rehabilitation sciences and psychology (JE-K, undergraduate student). Each interview was audio-recorded and transcribed verbatim.

Using an iterative process, the researcher utilized previously captured knowledge to assist with subsequent interviews and ask additional questions.

2.3.2 Data analysis

Two members of the research team (JE-K, a psychology student, and BD, a kinesiology student) coded the data following coding guidelines based on the Theoretical Domain Framework (TDF; 13). The descriptions of the TDF domains were modified slightly from the original descriptions to fit the scope of this project (see Table 1). The researchers first individually identified the information broadly into categories as being an "enabler" (something that supports the initiative), "barrier" (an obstacle to implementing the initiative), or "neutral" (perceived as important information that is not directly an enabler or barrier). These categories were later grouped into subcategories representing an adapted version of the TDF approach, and each researcher coded data into the TDF subgroups.

The second phase of coding involved collapsing together the separately coded interviews to compare and review the similarities and/or differences in coding that emerged. The codes were classified following the adapted TDF approach, although information could be coded in more than one domain. A list of recommendations for implementing an interdisciplinary experiential learning program was made based on the categories and subcategories. This list was sent to an individual from each stakeholder group so they could review the recommendations and provide any additional comments or suggestions for member checking.

3 Results

A total of 12 participants were interviewed with each stakeholder group consisting of 3 participants, and the length of interviews ranged between 30 min and 90 min. The results of this study placed the domains of the TDF into three major themes regarding the implementation of an interdisciplinary experiential learning program within rehabilitation centres. The overarching themes were (1) enablers, (2) barriers, and (3) program development (see Table 2). The TDF domains were categorized as representing a certain theme based on the highest coding proportion they had within that theme (e.g., environment/resources accounted for a greater proportion of barriers than either enablers or neutral).

Table 2 describes each stakeholder group and participant title/role with their coding ID to help indicate which stakeholder group each quote represents. The various quotes that represent the perspectives of implementing a new program in alignment with the TDF approach are shown in Table 3. The coding coverage for each domain categorized under each of them is represented in Appendix C.

TABLE 2 Description of stakeholder group, role, and coding ID.

Stakeholder group	Role description	Coding ID
Rehabilitation centre leaders	Oversee the programs at the rehabilitation centre and coordinate them	H01—Rehabilitation Coordinator H02—Physician H08—Nursing Leader
Clinicians	Supervise students from different health disciplines (e.g., physical therapists, physicians, and nurses)	C03—Physiotherapist C10—Occupational Therapist C12—Speech Language Pathologist
University clinical coordinators	Work within the university and are responsible for organizing the programs and ensuring that the program fits both the university and rehabilitation centre's standards	U04—Academic Coordinator U06—Academic Program Manager U11—Experiential Learning Coordinator
Students	From several health and rehabilitation areas and have already had a practicum experience	S05—University Alumni Student (Practicum student) S07—University Alumni Student (Independent study student) S09—University Alumni Student (Practicum student)

TABLE 3 Participant quotes representing each TDF domain (13).

Quotes		
Theme	**TDF domain**	**Quote**
Enabler	Reinforcement	H02: "there's some feasibility- the good news from our side of it, from the planning perspective- is we have almost complete control over the schedules that we put together when students rotate at [rehabilitation centre], so it's easy for us to make those changes from a planning perspective" H01: "showing how it's good for patients, their families, clinicians, and students then that helps with buy-in because it is something that our organization would be supporting so I think that that would help down the line"
	Beliefs and consequences	C10: "I think it is worthwhile to have the interdisciplinary approach because perhaps you're going to have students coming into professions with a more clear understanding of what the profession is about. And I think, I think if it improves patient care, which I know it does, then we should all be for that" U04: "why we want this initiative, it's the student learning and preparation for practice but then that is ultimately feeding back into that patient outcomes so I mean, are we really benefitting the patients and the clients. Yeah, I don't know- students and patients"
	Optimism	U04: "there's interest, there's momentum, there's engagement and those are kind of the key things. So, I think that it is absolutely feasible because it's not just kind of one person driving the initiative, we have a whole team so I would say "yes" for those reasons"
	Professional identity	H08: "[Hospital network] is definitely- that's one of the strategic directions or Mission/Vision values type of thing is to support- to be a partner with an academic center and be in support of student experience and I think doing it in an interdisciplinary fashion would also be like supported"
	Knowledge	U11: "Interdisciplinary experiences, I think can be super valuable because they simulate a lot more of like, what the real world is and probably more of like, like, if they were working at [rehabilitation centre] not as a practicum student but as an employee or researcher" C12: "We're constantly raising awareness when we have practicum students in the building, raising awareness of our own disciplines. Uh, or raising awareness, uh, within the patients of, uh, things that may help them"
	Skills	H01: "being open minded, willing to participate in development, and offering ideas, working well in a team because typically we have more than one student, so they have to work well with others" S09: "collaboration is kind of the name of the game in interdisciplinary practices" U04: "we want students who are passionate, interested, curious, and so having students apply for such a placement increases that engagement a little bit and that has worked well for multiple initiatives that we've run already"
Barrier	Environment/ resources	H08: "it's more like the actual feasibility, like the logistics, the how-to, the who is going to be involved, how it's going to impact our staff, like that's where the leaders would come with more of a that that like the cost"
	Beliefs and capabilities	C10: "the barrier is and you'll probably hear this that, oh, it's hard enough just to get an OT placement and asking if they, can we, is there request to clinicians to add another placement request for say a medical resident or social work student to come and observe me and all of us on our team, the social worker, the speech path, the physio sometimes, the assistant, we might all have students at different times, so, we already feel like we're tapped out with having students" C10: "it's just our days are jam-packed with day clients and writing notes and it's all slowed down by having a student because then it's taking- you want to explain things"
Program development	Goals	C03: "helpful to have someone who was trained on the frontline and kind of understood how that worked but then was almost like a liaison between the frontline staff and some of the management pieces" U06: "having the conversation about building these opportunities out is how do we back that down into the curriculum to ensure that interdisciplinary fourth year experiences are really valuable to students and they have the skills and knowledge to really, you know, apply that in fourth year." U11: "it's like how you package it, and how you talk about it and how you present it to people. It's super important … It is new so like how you roll it out and how you tell the story of it I think is really important"
	Evaluation	H08: "focus group or surveys, maybe having some baseline and then having the students go through the program and then repeating maybe a survey and have some focus groups to kind of share their reflections and maybe some reflective practice throughout the experience"

3.1 Theme 1: enablers

Codes were identified as being *enablers* when participants mentioned anything that would support the implementation of an experiential learning program or when the participant had a positive outlook about the factor. The following TDF domains were identified as being *enablers*: reinforcement, beliefs and consequences, optimism, professional identity, knowledge, and skills.

3.1.1 Reinforcement

Reinforcement was represented as anything that was foreseen to help support or hinder the startup and continued participation in the program (e.g., motivation, enthusiasm, and incentives). The focus is on what things can foster a continuous drive to engage and be a part of the program. Overall, there was a description of support from the key stakeholders in terms of initiating an interdisciplinary experiential learning program. All participants recognized the benefits this program could have on learning and patient outcomes within the healthcare environment for students, hospital staff, and patients, which facilitates motivation and incentives to engagement. One student described a practicum course positively saying that it “didn’t feel burdensome unlike some of my classes. So yeah. So that was great. It was like a little break like in a weird way. Yeah just such a change of pace from the usual academic” (S09).

Ensuring student programs support patient care is crucial as one hospital leader said “showing how it’s good for patients, their families, clinicians, and students then that helps with buy-in because it is something that our organization would be supporting so I think that that would help down the line” (H01).

Not only was there support on a personal level, but from a university organizational perspective, one coordinator said “I think we’re, we’re ready. We’re willing, I think, um, students are looking forward to it. It’s timely given sort of the conversations we’re having around the undergraduate curriculum. We have experiential learning coordinators, one now focused on partnerships and so I think, you know, there’s a lot of moving parts that now align really well with helping support moving this forward” (U06).

3.1.2 Beliefs and consequences

Beliefs and consequences were described as opinions or thoughts on what outcomes could come from this initiative and then extend beyond the participation of the program. This domain focuses on just the acknowledgement and perception of a potential outcome (positive or negative). The participants mentioned more favourable outcomes than negative ones, which highlighted the positive impact on students, clinicians, patients, and the organizations associated with this initiative. Increased workload on supervisors and clinicians was mentioned but many stated that having a strong student can help with assistance and ultimately aid in providing better care to patients.

One clinician noted that, with an interdisciplinary experiential learning program, “the outcomes are just going to be better. Because patients feel heard, supported from all parts of who they are, and when an interdisciplinary team’s there” (C12).

All stakeholders recognized the importance that this interdisciplinary program holds for participating students as they can “gain the confidence early on or opportunities to see what [they] like or what [they] don’t like or what [their] strengths are-that maybe [they] wouldn’t have an opportunity to do that before I personally think is a really important part of learning and probably the university experience” (H01).

3.1.3 Optimism

Optimism was described as having confidence in the program’s development and/or its values and goals. The participants were confident in the program’s values, and all of them highly rated the importance of having an interdisciplinary experiential learning program.

Students were especially supportive of this initiative with one saying it “was truly probably the most valuable experience I took away from undergrad. So, I think it would be really important to make sure future students get that same thing” (S09). Clinicians also noted how beneficial this type of program is when students are “physically getting in there and getting your hands on things. So, I think that as an overall learning experience for the students, I think it’s kind of unmatched” (C03). Another participant noted that “it’s not just feasible, it’s probably necessary” (C12), in terms of providing these types of learning opportunities to students in rehabilitation centres.

3.1.4 Professional identity

Professional identity relates to the extent to which implementing an interdisciplinary experiential learning program aligns with one’s personal or professional values. All participants agreed that this initiative lines up with their ideals either in a personal/career path manner (e.g., personal beliefs or help with future aspirations) or in a professional/organizational sense (e.g., organizational mission or strategic planning).

Integrating an interdisciplinary experiential learning program incorporates values from both the hospital and university perspectives. One hospital leader noted that a goal is to “promote here at [hospital network], you know, partnership and collaboration, and team approach, and involving a patient and caregiver and that kind of thing. So, I think definitely aligns with what the organization wants to see” (H08). From the university’s perspective, “this initiative definitely lines up with some strategic priority, not just within the [School] but broader within the [Faculty]” (U04).

Students also recognized the value of participating in an experiential learning opportunity for their future professional identity, as one explained that “really getting to experience it and observe it all was yeah, so so important, I think for shaping the kind of clinician I want to be down the road and even more broadly, the kind of person I want to be, like my professional identity wise” (S09).

3.1.5 Knowledge

Knowledge was classified as anything that involved an individual, mainly students, gaining more knowledge of what interdisciplinary care is and how to work within an interdisciplinary setting.

One student said that "it can only add to like their experience, learning in the practicum and just give them more of an idea of what they might have to do after school" (S07), and another mentioned how students could take their "knowledge and kind of disseminate it into the general community, in the public to greater inform, you know that every day, lay people about the different interdisciplinary healthcare professions is also kind of a more valuable component of it" (S09).

One hospital leader noted that from the students' perspectives, they can "increase their comfort level, increase their understanding and knowledge, increase their confidence. In you know, how to like, appreciating different disciplines and their roles and how they work and so on and being able to and how they contribute and be able to actually do that on- with mentorship from the clinicians. And appreciating the team approach and following that study" (H08).

Overall, having an interdisciplinary experiential learning program could promote "increased knowledge and understanding of the interdisciplinary team approach of what various team members can contribute. And increased maybe confidence in how the interdisciplinary care can be delivered" (H08).

3.1.6 Skills

Skills were coded whenever participants mentioned what they believed would be ideal or desirable skills for incoming students to have. Most participants deemed collaboration and communication as key assets to have, as well as being able to work professionally and adapt to changing situations. They noted the benefit of students having an interest and bringing enthusiasm with them when working with the clinical team and helping with the care of patients.

Various types of skills were noted to be critical for students to be "adaptable to changing situations or are able to be flexible, because a lot of these things it's hard to predict what exactly they're going to look like so you need a student who is okay with learning on the fly or things changing" (H01), to have "curiosity and initiative" (C12), and to have "super soft skills regardless of what they choose to do. It's like you were working collaboratively, you have to create like think critically and like work in teams, and in like interdisciplinary environments" (U11). Some student stakeholders reflected that students should be "interested or open to participating in this and being motivated to like meet other people through this program" (S07) and be able to "foster, facilitate the development of students who are able to function well in a team, communicate efficiently, professionally, and kind of convey their messages well, accept feedback graciously and have kind of an invested interest in self-improvement and self-reflection" (S09).

3.2 Theme 2: barriers

The codes were identified as being *barriers* when participants mentioned anything that would hinder or prevent the implementation of an experiential learning program or when the participant had concerns about the development or impact of this initiative. The following TDF domains were identified as being *barriers*: environment/resources and beliefs and capabilities.

3.2.1 Environment/resources

Environment and resources were depicted as any structural or organizational circumstances that may help or hinder the implementation of an experiential learning program. Most barriers were indicated as being environmental or resource issues. Many participants mentioned that this initiative could be burdensome to students and clinicians, which could counteract the benefits. One student participant recognized that "students are very very busy and same with clinicians" and if the program was voluntary, there "might just have less people showing up because of busy schedules" (S05). Similar concerns by supervisors as one clinician noted that there is the aim of trying "to get a lot of people in to experience but it can't be so much so that it's taxing on the clinician that we'd feel like we'd have to keep track of too many people and space" (C03). Not only the workload of different groups needs to be considered but also the planning and structure of the program as "the logistics and kind of how it would be done would need to be brainstormed and figured out" and how to "engage the stakeholders who would be like involved to help develop it" (H08). Another participant highlighted some key questions that would have to be considered such as, "who facilitates that [program], right? Like if it's an interdisciplinary thing like is that like a staff in one area? Like what does that workload look like?" (U11).

3.2.2 Beliefs and capabilities

Beliefs and capabilities were coded as the perceived ability to engage and be involved in this program. This was a foreseen barrier to the implementation of this program and many participants had concerns about the capacity that clinicians, students, and faculty members would have to implement and sustain this program. Concerns were mostly identified from the organizational/logistical side of implementing a new program into a hospital or ensuring that clinicians are not being overtaxed by working with students. There are a lot of considerations that need to be accounted for and working between two major organizations (i.e., hospital and university) can be a "large undertaking … to try to like, bring everyone together because there's just so many different stakeholders" (U11).

However, for students, many felt that participating in this program was achievable, especially if it is embedded into the curriculum. One student who was part of a practicum course said, "from the student perspective, I think if it's incorporated into the curriculum, then it would be easy. The minute you sort of require additional work I think that's where you might lose some of that buy-in" (S05).

3.3 Theme 3: program development

The codes were identified as *program development* when anything specific to the creation and planning of the program was brought up. Several participants mentioned various things that should happen before and during the program that would increase its sustainability and efficiency. This theme differs from the others as it focuses on the planning process and structuring of the new program rather than its intended outcomes. The only TDF domain that was classified in *program development* was goals. An additional subcategory was created, evaluation, as it was identified as an important factor to address when implementing any type of programming and to measure goal achievement.

3.3.1 Goals

Goals were ideas or suggestions made that would help achieve and support the desired outcomes of the program. Several participants noted some goals they would like to see happen when implementing a new program. This initiative involves a lot of people and coordination so having "someone who is trained and knows the frontline area but can also work to bring up kind of the important issues to management and work to help them and come up with strategies to implement" (C03) is a key aspect to consider. Engaging students early on in their academic career was also noted as something that could be beneficial as it helps in "providing some background as to what might be expected of them and having students apply I think is a great thing and really speaks to including students that would be a good fit for some of the things, especially in the early stages" (U04).

3.3.2 Evaluation

Evaluation was not originally in the TDF as a domain but was added to this study to further understand the appropriate methods to measure the success and progress of this program. One hospital leader noted some things to consider when measuring the success of the program which include, "are our patients satisfied, we've improved the care that they received, either by decreasing the waitlist, increasing our volumes, while not like overtaxing the staff, and improving the experience of students" (H01). The participants also mentioned that having feedback from the different groups involved (i.e., students, preceptors/supervisors, and patients) is important, particularly when it is reciprocal. One student mentioned that it is "great for feedback to work in both ways so that we can also give some feedback to the, like our preceptors" (09). The participants mentioned some evaluative methods which could include focus groups, surveys, online discussions, or reflections as ways to provide feedback back to students or preceptors and to help inform how the program is running.

4 Discussion

The findings of this study inform the implementation of an experiential learning program with an interdisciplinary approach. The results contribute to understanding what supports, encourages, or hinders the development and implementation of a new program at a rehabilitation centre and what is needed to appropriately roll out this initiative. Although this study focused on the barriers and enablers, many of the participant's comments addressed considerations for the development of the program. Most findings were positive, and this type of program is believed to have a beneficial impact on several groups, including students, clinicians, and patients. Having an interdisciplinary experiential learning program aligns with both the hospital and the university's strategic priorities and therefore creates a positive impact for the involved organizations. However, there were some logistical concerns about implementing a new experiential learning program within an existing rehabilitation centre.

To address these concerns, a set of recommendations were made to help with the development and implementation of an interdisciplinary experiential learning program at rehabilitation centres (see Table 4). It should be noted that this study took place just after COVID-19 restrictions, which had lasted around two years, started to be lifted. Many participants mentioned the effects that COVID-19 had on the rehabilitation centre, educational experiences, and/or their personal lives. Most feedback did not pertain to the specific effects of COVID-19, but issues such as safety concerns and spacing issues were brought up with the pandemic in mind.

4.1 Enablers

The results indicated that there are several benefits to incorporating a collaborative and engaging program in hospitals. These include enhancing student involvement and knowledge in clinical healthcare settings which aligns with previous research on the benefits of hands-on experiences (5).

Recommendations were made based on the *reinforcement* codes, which were to plan the structure and process of placements well ahead of students being onboarded and to spread awareness of the successes achieved through the program after implementation. Doing so will help with organization, provide a smooth transition, and showcase the benefits of implementing an interdisciplinary experiential learning program to various groups (e.g., students, clinicians, patients, and organizations). This work will facilitate the sustainability of the program and re-involvement of participating parties when new programming occurs. To produce enabling *beliefs and consequences*, encouraging proper understanding of interdisciplinary settings and the various disciplines involved in health care can further support students' engagement in their learning. These findings align with previous research where students were reported to enjoy working collaboratively as it helps with understanding, problem-solving, and providing better patient care (5, 18). If students can optimize their contributions, patient care can be positively influenced and allow for a holistic approach (19). *Optimism* in this type of program was achieved when the timing was optimal for all parties involved. If the timing and management work for all organizations, confidence in the success of this program increases drastically, especially when there are pre-existing programs associated with the hospital/

TABLE 4 List of recommendations for implementing an interdisciplinary experiential learning program.

Recommendations		
Theme	TDF domain	Recommendations
Enabler	Reinforcement	a. Discuss planning of student placements well in advance b. Share testimonials of successes from the program
	Beliefs and consequences	Encourage interdisciplinary approaches and understanding of various health professions and disciplines to support students in a clinical and academic setting
	Optimism	Determine an optimal time for rehabilitation centres and educational institutions to start planning and implementing an experiential learning program for students
	Professional identity	Incorporate institutional priorities/values (e.g., strategic planning)
	Knowledge	a. Encourage students to reflect on their future goals/desires and how participating in an interdisciplinary program can support those goals b. Spread awareness and understanding to clinicians on how supporting learners can aid patient care and their own experiences/knowledge
	Skills	Identify students who are highly interested and professional, and can collaborate and communicate effectively
Barrier	Environment/ resources	Discuss logistical barriers (e.g., cost, processes, facilities) and develop a strategy on how to address foreseeable issues (e.g., staff impact, structure)
	Beliefs and capabilities	a. Focus on reducing clinician burden, or perception of burden b. Reflect on how to best transition students to a healthcare setting
Program development	Goals	a. Embed into current curriculum early on in undergraduate career (1st or 2nd year) to help inform their choices in upper years and post-graduation b. b. Have someone who can champion and oversee the program (e.g., manage between the hospital and university or between frontline and leadership teams) c. Consider the promotion of the program and how to properly inform/engage students (especially if it is a new program)
	Evaluation	Utilize feedback and reflections from students and preceptors/supervisors involved in the program

educational institution. Ensuring that organizational values and mission align with the proposed program and maintaining a *professional identity* by incorporating institutional priorities and strategic planning is crucial. Aligning the program's values with the associated organizations can enforce the significance of the program as well as produce a reciprocal and mutual benefit to all parties involved (20, 21). The factors that would increase *knowledge* in participating individuals include having students reflect on how engaging in an interdisciplinary experiential learning program can support their goals. If members are motivated by the initiative, learning will result in an increased understanding of interdisciplinary healthcare settings. Another recommendation was to spread awareness of the benefits of employing an experiential learning program to clinicians and/or supervisors in particular, so they can help educate incoming students and work towards enhancing patient care. These findings are similar to the study by Van Wyk et al. (19), where the authors found simulating an interdisciplinary setting can encourage students to work more effectively within multiple disciplines. The participants mentioned several *skills* they would like students to have and how identifying students who are strong in these skills (e.g., teamwork, collaboration, motivation, communication, and professionalism) will support the viability of the program.

4.2 Barriers

The findings demonstrate that there are logistical concerns that need to be addressed before implementing a new program. This would include *environmental/resource* barriers, which could be addressed by having discussions about costs, having access to facilities (e.g., space, capacity, and safety), and sorting out appropriate processes (e.g., onboarding of students, dealing with challenging students, and facilitators). With new programming, there will be an extra cost to taking on a new initiative and embedding it into practices (5). These costs could be monetary but also from other resources such as time, energy, and coordination. It is important to have strategies in place on how to address these issues before they arise. Along with costs, organizing the use of facilities (rooms being used, spacing within rooms, etc.) needs to be decided on as there will be additional people within the rehabilitation centre. For both issues, determining and regulating the processes are key to developing sustainable programming. Additionally, clinicians who would be supervising the students need to feel supported and confident in who is assisting them and not overly burdened. Additional programming is a large commitment and takes many resources from various areas such as staff members, students, and organizations (22, 23), which is why there needs to be a focus on reducing this potential burden. The perceived *beliefs and capabilities* of involved members need to have minimal risk to decrease the reservations that clinicians have about supervising students. There also needs to be uptake in students who are motivated to take part in this kind of initiative, which means planning out and communicating with students about how they are going to be supported in their transition into a healthcare setting.

4.3 Program development

The potential outcomes of a program are another crucial consideration in the development of a new program and how it is structured. With multiple disciplines involved, the way the program is rolled out and how everyone will be coordinated will affect how successful it is in delivering enriched education and optimal patient care (5). There were several *goals* that participants had mentioned they would like to see achieved prior to or during the implementation of this program. One, the program would be embedded within the student curriculum and would occur early on in either the first or second year of training. As Salvatori et al. (24) noted, coordinating student timetables is an obstacle, and uptake is difficult when students perceive it as additional work on top of their academics. This aligns with what university clinical coordinators mentioned in this study, which is to embed the program within student academics and introduce it in the earlier academic years. This will help students make more informed career choices and have a better idea of future directions in their later years of training. A second goal is to have someone champion or manage/oversee the program to help organize and orient students/supervisors. Lastly, the topic of how to properly promote the program and entice students to get involved in this initiative was mentioned. Since this would be a new program being offered, uptake may be difficult to achieve in the beginning. Similarly, Copley et al. (23) highlighted the importance of promoting interprofessional education and how framing can help support implementation within clinical practices. Offering an experiential learning program to students can have significant benefits to the participating parties, but if the initiative is not packaged engagingly, enrollment and retention will be difficult to maintain. Another recommendation was regarding the *evaluation* of the program and what potential methods could be used. This sub-theme was not originally part of the TDF but was an additional consideration as evaluating programs is important to the implementation and sustainability of a program (25). Receiving feedback from a variety of perspectives such as hospital leaders, university clinical coordinators, students, and clinicians is an important step to take to ensure that the program is supporting all parties as well as providing beneficial learning and care outcomes. This is especially important since different stakeholders will be interested in evaluating different components of the program and analyzing various metrics. This finding aligns with previous research that notes the importance of allowing reflection to occur for experiential learning opportunities to help improve the structure of the experience (22).

4.4 Limitations

A limitation of this study is the reduced generalizability of the findings to other regions due to the sampling methods employed. The data captured stems from the participants who were all currently working at the same rehabilitation centre or were affiliated with the same university institution. While there was representation from different disciplines (i.e., *clinicians*—speech and language pathologists, occupational therapists, and physical therapists; *rehabilitation centre leaders*—spinal cord injury rehabilitation navigator, physiatry, and nursing), it is acknowledged that not all voices within a rehabilitation centre were included in this study.

4.5 Future directions

This study provides insight into the development of an interdisciplinary experiential learning program at rehabilitation centres. Although this study was based in Ontario, the information and knowledge provided can be generalized to other Canadian institutions and organizations. However, future research should focus on expanding outside of the Canadian context as well as implementing pilot interdisciplinary experiential learning programs. Further research in this area could result in a change in academic curricula to include more interdisciplinary experiential learning for students. Offering more opportunities to gain practical skills and knowledge will facilitate the development of healthcare providers and leaders which will in turn enhance patient outcomes in rehabilitation centres.

5 Conclusion

In conclusion, the benefits of providing an interdisciplinary experiential learning program at rehabilitation centres significantly impact several groups and can positively affect organizations as well. Understanding the various considerations that could further enhance or hinder the implementation of this program is key to optimizing the outcomes and providing better experiences and patient care. Overall, this study provided valuable insight into the potential enablers and barriers to developing an interdisciplinary experiential learning program for university students within rehabilitation centres. This initiative could further enhance educational curriculums, student and clinical experiences, patient outcomes, and organizational goals. Through this qualitative study and multi-perspective lens, the presented recommendations provide key areas to focus on while developing and maintaining experiential learning programming.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Western University Health Sciences Research Ethics Board and Lawson Health Research Institute Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

JE-K: Data curation, Formal Analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. BD: Data curation, Formal Analysis, Writing – review & editing. DW: Conceptualization, Investigation, Supervision, Writing – review & editing. JU: Conceptualization, Investigation, Methodology, Project administration, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Appendix A

Semi-structured interview guide

What is your profession or role?
(Rehabilitation centre leader, clinician, university faculty/staff, or student/alumni).
How many years have you been in your role (years of experience)?
The rest of the questions are more specific to the implementation of a new interdisciplinary approach.

1. Do you think there is a need to create an interdisciplinary approach to support the programs already established?
2. Do you think there are reasons why there is not already one? Please elaborate further. (Prompt—awareness of existing barriers, knowledge from other experiences)
    - ○ Rehab leaders: Are there procedural or organizational barriers at (rehabilitation centre)?
    - ○ Clinicians: Is there a lack of supervisors available to take on students? Is it not a preferred approach?
    - ○ University faculty/staff: Would a placement like this be doable—would it fit within the curriculum?
    - ○ Students/alumni: From your experience, have you gained valuable experience/knowledge?
3. What types of experience or skills should students have to increase the quality of this approach? (Prompt—previous student experience, level of education, personal interests)
    - ○ Rehab leaders: Specific qualifications needed at (rehabilitation centre)?
    - ○ Clinicians: How are students assigned a supervisor?
    - ○ University faculty/staff: What was the process for students to take the experiential learning course before?
    - ○ Students/alumni: Have previous experience?
4. Based on your past experience/placement, do you think the implementation of this approach is feasible? (Prompt—physical location, cost, support, skills, travelling/commuting)
    - ○ Rehab leaders: Can placement for students work with staff and within (rehabilitation centre)? (Physical location, cost, hospital overseeing/supervision)
    - ○ Clinicians: Do you think enough staff would agree to work with students? How about patients? (Staff support, patient agreement)
    - ○ University faculty/staff: What things would need to be included to fit with the curriculum? (Educational policies)
    - ○ Students/alumni: Could you see yourself being able to fully commit to this approach? (Travelling time, time management, motivation)
5. Would this approach align with your professional identity or with the organization's mission/vision?
    - ○ Rehab leaders: (Rehabilitation centre)/hospital or specific program
    - ○ Clinicians: Any health staff member in the program you work in
    - ○ University faculty/staff: University or faculty or department
    - ○ Students/alumni: Student, i.e., the program you are in or went through
6. How easy or difficult would it be for you or your organization to engage in this approach? (Prompt—time management, larger care team, more communication, independence, etc.)
    - ○ Rehab leaders: (Rehabilitation centre)/hospital—policies, cost
    - ○ Clinicians: Staff members—workload, patient care/care team, communication
    - ○ University faculty/staff: University—policies, consistency, curriculum, cost
    - ○ Students/alumni: Student—time management, workload, cost
7. How confident are you that this approach would be beneficial? (Prompt—pertaining to skills, patients, working/learning environment)
    - ○ Rehab leaders: At (rehabilitation centre), help with other initiatives/programs
    - ○ Clinicians: To student learning, work environment, cohesiveness/teamwork
    - ○ University faculty/staff: Help with curriculum, easier to add similar approaches in the future
    - ○ Students/alumni: Adding to your skills/experience, exposure to new environments/people
8. What outcomes do you think could occur after implementing an approach like this? (Prompt—are these outcomes negative or positive? Short-term or long-term?)
    - ○ Rehab leaders: Adds complications at the hospital, navigating issues—other approaches can be implemented
    - ○ Clinicians: Communication, workload, patient care
    - ○ University faculty/staff: Fit with curriculum
    - ○ Students/alumni: Skills or experience achieved or lacked
9. What do you think the goal of an approach like this should be? What would success look like?
    - ○ Rehab leaders: More exposure to (rehabilitation centre), a successful approach to ensure projects are completed with more perspectives, and that can be incorporated into other programs

   - ○ Clinicians: Help guide aspiring students, patients benefit
   - ○ University faculty/staff: Beneficial learning experience
   - ○ Students/alumni: Help with student experience, more exposure, working with a bigger team and other students

10. How should this approach be evaluated?
    - ○ Rehab leaders: Could this approach help with the hospital's organization? What is the key metric you would use to evaluate the program?
    - ○ Clinicians: What would you think should be measured to indicate if this is helping?
    - ○ University faculty/staff: What is the key metric you would use to evaluate the program?
    - Students/alumni: Based on your previous learning, would using a more interdisciplinary approach enhance your overall practicum experience and skills? What should be measured to determine if this has been helpful?
11. On a scale from 1 to 10, 10 being the most important, how important do you think it is to create an interdisciplinary approach to experiential learning? Can you elaborate on why?

Appendix B

TABLE B1 Coding guidelines.

TDF Domain	Barriers	Enablers
Knowledge	• Lack of knowledge • Different kinds of knowledge/understanding	• Extra insight or knowledge • Consistent understanding across teams/organizations
Skills	• Lack of skill or training (inexperience)	• More practical experience
Environment	• Physical environment • Economic feasibility • Time management • Distance from location • Attitude differences	• Economic and organizational support • Physical location is feasible • Support from other members and patients
Professional identity	• Different organizational mission • Does not align with professional identity	• Complementary organizational missions • Helps with professional role/aspirations
Beliefs and capabilities	• Lack of belief in abilities (for each role) • Boundaries to one's capabilities (personal and organizational)	High confidence in being effectively involved with the program
Optimism	• Program won't aid (list specifics)	• Program will aid (list specifics)
Intentions	• Low belief in the importance of the program	• High belief in the importance of the program
Goals	• Lack of goals	• Stated goals that help students, faculty, and patients
Beliefs and consequences	• Negative outcomes • Worries and concerns	• Positive outcomes
Reinforcement	• No incentives	• Intrinsic motivations • Extrinsic motivations

Appendix C

TABLE C1 Coverage of each TDF domain within each overarching theme.

TDF domain	Enabler $N = 567$	Barrier $N = 207$	Neutral/program development $N = 360$
Environment/resources	$n = 301$ (53%)	$n = 165$ (80%)	$n = 155$ (43%)
Reinforcement	$n = 245$ (43%)	20 (10%)	35 (10%)
Beliefs and consequences	$n = 203$ (36%)	14 (7%)	24 (7%)
Optimism	$n = 184$ (32%)	9 (4%)	0
Professional identity	$n = 174$ (31%)	26 (13%)	36 (10%)
Goals	$n = 172$ (30%)	15 (7%)	163 (45%)
Knowledge	$n = 140$ (25%)	35 (17%)	41 (11%)
Skills	$n = 119$ (21%)	17 (8%)	50 (14%)
Beliefs and capabilities	$n = 78$ (14%)	69 (33%)	42 (12%)

Quotes may be coded in more than one TDF domain and may have some overlap. Percentages will not equal to 100.

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Bone health education in individuals with spinal cord injury or disease—the Bare Bones Podcast Series: plan it, produce it, post it!

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Introduction: The Consortium for Spinal Cord Medicine's inaugural Clinical Practice Guideline for Bone Health and Osteoporosis Management for Individuals with Spinal Cord Injury or Disease (CSCM-CPG) was published in 2022 for a clinician audience. The aim of this project was to develop a podcast series to ensure people with lived experience with Spinal Cord Injury or Disease (PLEX) understand the CSCM-CPG content and know how to act to reduce their fracture risk.

Methods: The "Bare Bones Podcast Series" consists of nine episodes; one related to each CSCM-CPG chapter. The podcast content and the questions asked in each podcast were co-developed by PLEX partners (PLEX-P) and the project team. Two PLEX-P acted as co-hosts for the series. The invited speaker(s) were CSCM-CPG expert panel members who participated in an informal dialogue with the hosts. Each podcast closes with a specific action a listener can do to advance their bone health. The related Educational Action Planning Tool (EAT) handouts contain text and infographic information specific to each podcast episode and include key concepts and a specific actionable take-home message. Local PLEX reviewers (PLEX-R) were invited to review podcast episodes and EATs and provide their feedback through focus group participation or one-on-one (1:1) interviews. The project team revised the podcast episodes and the EATs based on feedback from the PLEX-R prior to releasing them online.

Results: Nine podcast episodes and related EATs were designed and created collaboratively with 3 PLEX-P, 22 PLEX-R, 11 CSCM-CPG expert panel members, and the project team. The episodes were titled: "Introduction to the Bare Bones of Bone Health"; "Fracture 101"; "Blood Tests—a Window into You"; "I See Your Skeleton"; "Vitamin D for all, Calcium for Some"; "Get Moving and Loading"; "Pills or Poisons & Atomic Habits"; "Snap and Crack"; and "Directions for Research". The Bare Bones Podcast Series was shared through the project website.

Conclusions: The podcasts will aid PLEX and their family caregivers to advocate for ongoing bone health assessments and to promote an ongoing dialogue with care team members regarding how to prevent fractures and fracture-related morbidity and mortality.

KEYWORDS

Co-design, patients with lived experience, bone health, patient education, fracture, osteoporosis, Spinal Cord Injury

Introduction

There is a compelling need for individuals with Spinal Cord Injury or Disease (SCI/D) to understand the etiology of fragility fractures and to actively work to mitigate the adverse health consequences of fractures. Fragility fractures are defined in spinal cord injury (SCI) as those that occur after a fall from standing or seated height, or less, or in the absence of trauma such as during routine activities of daily living (1). Fragility fractures are common problems that increase the morbidity and mortality of individuals with SCI/D (PLEX). In the first 12–18 months after SCI, individuals with motor complete injury experience substantial (30%–50%) declines in bone mass of the hip and knee regions (distal femur and proximal tibia regions), predisposing them to a lifetime of increased risk of lower extremity fracture. Fractures of the proximal tibia, distal femur, and hip regions are the most common, with the median time to first fragility fracture typically being at 8.5 years post injury among those with traumatic SCI (2). Approximately 2%–5% of individuals with traumatic SCI experience a lower extremity fracture each year, with a lifetime incidence of 25%–50% (2–5). Fracture rates vary in the SCI population between 2.14 and 3.2 fractures per 100 patient-years (4, 6–8). Women with SCI over age 50 are at higher risk of fracture than younger women, or men of any age (hazard ratio: 1.54, 95% CI: 1.12–2.11) (9). Fractures commonly occur after a fall from standing or from seated height onto a flexed knee, or from rotational stress on the distal lower extremity during routine activities of daily living (10–15).

Low bone mass and elevated fracture risk are not clinically problematic until a fragility fracture of the hip, distal femur, proximal tibia or distal tibia regions occur. Unfortunately, fractures after SCI/D do not always heal well, and many PLEX experience poor outcomes, including delayed union, non-union, limb malalignment, segmental shortening with pseudoarthrosis, or amputation. Fractures among PLEX, whether managed operatively or conservatively, result in increased secondary health complications including respiratory infections, pressure ulcers, urinary tract infections, delirium, and venous thromboembolic events (5, 6). Additional complications of fracture include: autonomic dysreflexia, pressure injuries, pin site or joint infection, spasticity (16), and shoulder pain with depression (9, 17). Carbone et al. have reported that in a study on a cohort of 12,389 male veterans with traumatic SCI for at least 2 years, lower extremity fractures were associated with increased 5-year mortality. The risk of mortality was greater in men over 50 years of age (HR: 3.42, 95% CI: 2.75–4.25), men with motor complete injury (HR: 3.13, 95% CI: 2.19–4.45), and men with a high Charlson Co-morbidity Index (HR: 1.11; 95% CI: 1.09–1.13) (4).

Thus, it is crucial that patients and their care providers take a proactive approach to promote bone health, and prevent fracture and limit fracture-related health complications and impact on life expectancy when fractures occur given fracture-related morbidity (5) and mortality (4, 18). Bone health experts have collaborated to develop and publish three consensus documents regarding bone health evaluation and management following SCI/D: (1) International Society for Clinical Densitometry (ISCD) Position (2) Statement (19); (2) the Consortium for Spinal Cord Medicine's Bone Health and Osteoporosis Management in Individuals with Spinal Cord Injury Clinical Practice Guidelines for Healthcare Provider (CSCM-CPG) (1); and (3) the Orthopaedic Trauma Associations (OTA) Delphi Consensus on Fracture Management after SCI (20). These consensus recommendations represent collaborative efforts among healthcare professionals to improve bone health, by facilitating recognition and management of osteoporosis, fracture risk, and fracture diagnosis among PLEX. We recognize the need to bridge the gap between the guidance for clinicians and the ability of PLEX to understand, promote, and adhere to the new CSCM-CPG and related consensus documents.

Education to improve a patient's health literacy is a key to improving osteoporosis screening and/or treatment rates (21). Poor health literacy negatively impacts patients' health outcomes (22, 23) and affects key decision-making (24). Low health literacy can lead to physician communications being poorly understood, resulting in incomplete self-management and responsibility for bone health, as well as incomplete health service utilization (25). Common issues associated with current patient education materials include the following: (1) the majority of online health information lacks quality evidence, (2) the materials developed by healthcare professionals often overlook important information needed by end-users, and (3) the materials may not be easy to access and/or user-friendly.

Patients tend to seek information, motivation, and support for healthy living and management of their health conditions via websites (21, 26, 27). Online health information is easily accessible, with a vast amount of information in a variety of formats that can help people stay up to date with emerging information about their health conditions, and websites can facilitate shared decision-making between patients and their healthcare providers (28). Unfortunately, much of the current online health information is not based on high-quality evidence and is therefore not credible (29–32).

"Co-design" has been introduced widely in the field of patient education and engagement. Co-design is a process in which targeted end-users and other relevant stakeholders form a partnership with researchers and work together on all aspects of intervention development, from understanding the needs of end-users, to content development, and pilot-testing of project outcomes (33). Involving patients in the co-development of educational materials improves the quality of existing and future health services, and empowers the patient to ask questions (34). Studies show patient-focused education materials have led to improved clinical outcomes (35). A systematic review reported patient education is an effective strategy to improve osteoporosis screening and/or treatment rates in the able-bodied population (21). Despite the recent value placed on health education materials co-developed by patients, there are few co-developed education materials in rehabilitation settings outside of the Veterans Administration and some of the more recently funded Craig H. Neilsen Foundation projects (36).

Finally, paper forms of patient education handouts or pamphlets have been a preferred method of sharing and obtaining information due to their convenience and availability (37). However, criticisms of brochures include concerns regarding the use of medical jargon and the high literacy level needed to comprehend the material. Krontoft conducted a survey to investigate patient experiences and preferences for different forms of education materials among able-bodied patients (38). The study found that most respondents (86.46%) would like a text-based format to be available; however, half of the respondents (50.21%) also wished for an audio–visual format, followed by approximately one-third (31.67%) who desired an audio format. Patient preferences for education materials vary with age and education level. However, the majority of respondents preferred to use combinations of written, audio, and video material.

To address the perceived need for relevant and actionable education materials, we planned to use co-design methods to develop the "Bare Bones Podcast Series", a collection of educational podcasts and related handouts based on scientific evidence, intended to be user-friendly, using clear and simple language (handout) and audio (podcast) formats that are accessible to PLEX and their family caregivers throughout North America. These podcasts and handouts are intended to aid PLEX to better understand their bone health, fracture risk and to provide education and context to PLEX prior to meeting with their healthcare provider. This ensures PLEX are well prepared with questions and expectations regarding bone health screening, treatments, fracture recognition, and options for fracture management. Shared decision-making is an essential component of bone health and fracture management for PLEX, and a working knowledge of the available therapies can help drive best-practice implementation.

A podcast is a combined digital audio file of speech, music, broadcast material, etc., made available on the internet for streaming or downloading to a computer or portable media player (39). It is similar to the traditional radio, except it is available on demand. Podcasting is a convenient and portable way to share knowledge as listeners can connect at their leisure. Educational podcasts are relatively inexpensive to produce and are among the most popular types. The format of a podcast is engaging and allows for active listening during leisure time or physical activity. Podcast series typically include an introductory episode, followed by content episodes, and a final episode that often includes a wrap up or series highlights. In the field of SCI/D, podcast series for several topics are available such as Activity-Based Therapy (40), American Spinal Injury Association (ASIA) SCI Science Perspectives (41), and International Spinal Cord Society (ISCoS) podcasts (42).

A handout, by definition, is an unbound leaflet used to provide health information on a single subject. Handouts are cheap to produce and can be readily distributed to PLEX in paper and e-formats suitable for distribution in hospital and community settings. We use the term Educational Action Planning Tool (EAT) throughout this article to describe the content and utility of podcast-related handouts.

Patient-centered care has its roots in the disability movement, which aims to change healthcare from within by facilitating partnerships among patients, families, and healthcare professionals and is based on the premise that informed patients are better able to advocate for appropriate and timely care (43). The Bare Bones Podcast Series comprises a podcast series and related EATs. The Bare Bones Podcast Series seeks to advance patient-centered care by empowering PLEX to be their own advocates. This includes making positive lifestyle choices to augment their bone health, selecting appropriate treatments, and reducing the prevalence of fractures and fracture-related morbidity and mortality. We hypothesized that the Bare Bones Podcast Series would be an effective means to educate PLEX and their family caregivers about bone health, osteoporosis, and fracture risk.

Methods

Methods overview

Our podcast and related EAT content were based upon the CSCM-CPG for healthcare providers, which is the most comprehensive clinical practice guideline (CPG) covering detection and management of low bone mass, osteoporosis, and fracture for PLEX among recently published consensus documents (1, 19, 20). The target audience for the Bare Bones Podcast Series was PLEX, their family, and caregivers living in North America who may not possess strong foundation knowledge related to bone health. The target audience for dissemination includes PLEX affiliated with the Paralyzed Veterans of America (PVA) and other SCI-specific non-governmental organizations, including ISCoS, ASIA, and the Canadian Spinal Cord Injury-Rehabilitation Association (CSCI-RA). The project team included three PLEX partners (PLEX-P) with prior media appearances and advocacy training who assured the content was relevant, and four project team members with scientific and methodological expertise in sublesional osteoporosis, diagnostic imaging, biochemistry, clinical research, podcast development, and knowledge translation related to PLEX. The project also involved the engagement of the CSCM-CPG Expert Panel members as episode guests and PLEX reviewers (PLEX-R) who were not part of the project team but contributed to reviewing the podcasts and EAT content.

In collaboration between PLEX and members of the CSCM-CPG Expert Panel, the objectives of this project were

1. to co-develop a series of nine freely available podcasts and related EATs that are accessible to PLEX, their family, and caregivers; and
2. to disseminate podcasts and EATs via an accessible website.

This project was approved by the University Health Network (UHN) Quality Improvement Review Committee. As the project falls outside the scope of research requiring Research Ethics Board (REB) review, ethics approval was waived by the committee and confirmed by a UHN REB Chair.

At the project outset, the team convened regularly to compile and assemble the podcast and EAT content. A statement of work for each PLEX-P was created for their role at the outset of the project. They received payment bi-annually for their contribution to the project. Figure 1 displays the Bare Bones Series Development and Evaluation Process Map. Briefly, the podcast key questions were identified and planned by the project team (Figures 1A,B). Podcast guests were oriented to the content and recording process. Each podcast was recorded featuring two PLEX-P acting as co-hosts and one or two CSCM-CPG authors/panel members as invited guests (Figures 1C–F). EATs were created to correspond with each podcast episode (Figure 1G). The project leader and team reviewed each podcast and EAT for clarity and accuracy of the content and alignment with the CSCM-CPG (Figure 1H). PLEX-R were recruited to review and provide their feedback on blocks of at least three podcast episodes and related EATs (Figure 1I). The project team revised and refined the podcast content and EATs based on the feedback from PLEX-R (Figure 1J). The finalized podcast episodes and EATs were disseminated via the project website (Figure 1K).

Podcast episodes

Planning the podcast

The podcast series structure was intentionally developed to mimic the CSCM-CPG Structure (Figure 1A). Team members (BC, MM, AK, HJ-R, LB, LAB, and WM) created a table outlining the number of episodes, title of each episode, key concepts, learning objectives, and episode descriptions. The opening taglines give listeners insights into the upcoming discussion with the episode guests, while not disclosing the actual take-home message. After each episode, listeners are provided with a take-home message or helpful tip they can keep in mind or act upon to advance their bone health. The taglines and take-home messages are designed to keep listeners engaged, in not just one episode of the podcast but the full series of informative topics, and to support the flow of information throughout the series regarding achieving healthy bones and a fracture-free life.

Generation of the interview questions

All questions posed in the podcasts were generated by PLEX-P (LB, AK, and WM) after reviewing the nine CSCM-CPG chapters (Figure 1B). The PLEX-P chose chapters they wished to review. Each PLEX-P was responsible for three chapters each. Their task was to select/generate pertinent questions that they felt adequately reflected the CSCM-CPG content and were important to managing bone health after SCI/D. Each PLEX-P created a list of questions for the chapter to be reviewed and shared with the

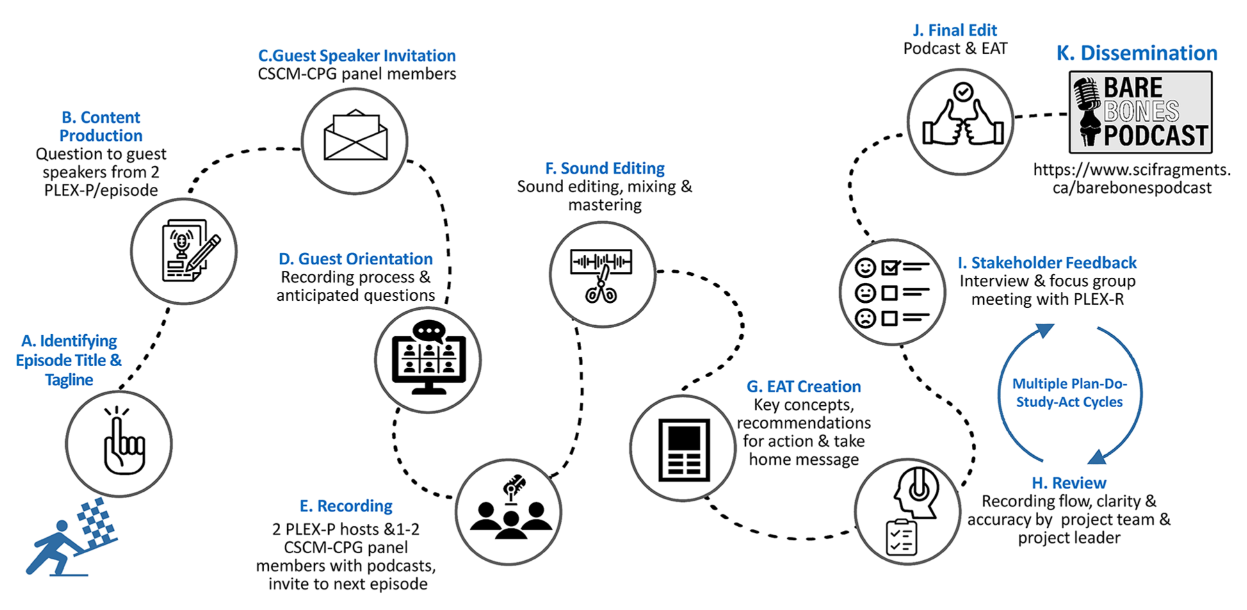

FIGURE 1
Bare bone series development and evaluation process map. (A) Identifying Episode Title & Tagline; (B) Content Productio; (C) Guest Speaker Invitation; (D) Guest Orientation; (E) Recording; (F) Sound Editing; (G) EAT Creation; (H) Review; (I) Stakeholder Feedback; (J) Final Edit; (K) Dissemination.

group as a mock up for the podcast discussion. From the generated list of questions, the most relevant questions were selected and refined for simplicity using plain language and posed in a conversational format during the podcast interviews.

Recruitment of expert guest speakers

Altogether 11 expert CSCM-CPG members from Canada and the US were invited to participate as guests in the Bare Bones Podcast Series (Figure 1C). All invited experts agreed to the podcast participation, with five of the nine episodes having two guest speakers. Prior to podcast recording, the guests completed a written consent form and were provided an information package outlining the episode structure along with the introductory tagline, list of potential interview questions, and take-home message to review specific to their expertise. Guests were provided a list of equipment they would need and instructions on how to join the web-based platform (Zoom, Zoom Video Communications Inc., San Jose, California, United States) and achieve clear sound during the recording. The guest speakers participated in a 1-hour planning meeting, led by the PLEX-P podcast hosts (AK and WM) and the co-producer (HJ-R) who handled the technical aspects of the podcast (Figure 1D). During the planning meeting, the co-hosts reviewed and discussed the material with the guest speakers, and revisions were made to the interview questions, introductory tagline, and take-home messages to reflect the information exchanged and focus on the most salient points. The co-producer (HJ-R) conducted an audio test and reviewed the equipment and set-up, and shared tips to produce high-quality sound.

Interview script development

Following the planning meeting, team member and podcast host (AK) converted the interview questions, introductory tagline, and take-home message for each episode into an interview script. Team member and co-host (WM) and the project leader (BC) reviewed the episode scripts and refined as needed. The script dialogue was framed in a conversational tone and worded in plain language. Scripts for each podcast episode followed a similar format: introductory tagline, introduction of co-hosts and guest(s), interview questions guided by hosts, take-home message, and information about the next episode, and where to locate the episode-related EAT.

Podcast recording

Prior to recording sessions, guests were sent email reminders regarding the equipment needed, instructions on how to log in to the Zoom and an audio checklist (Figure 1E). The guests were provided the episode script and asked to prepare talking points for the interview questions, keep the responses succinct, and providing responses in plain language while allowing for conversational dialog.

At the time of recording, the project team (AK, WM, and HJ-R) met with guests to orient them again to the recording process, do a dry run of the interview, and answer any questions they had prior to recording. The entire recording process lasted approximately 1-hour. The series hosts (AK and WM) alternated between the primary and secondary co-host roles across the podcast series. Episode one was recorded first as a pilot episode with project leader and guest (BC). The remaining episodes were recorded according to guest schedules and availability.

Sound editing and production

To develop the podcast theme music, the co-producer (HJ-R) presented four sound samples for the team to consider (Figure 1F). The project team selected three themes that were mixed into a sample introduction. After listening to the sample introductions, the team chose the podcast theme music.

Once recording of an episode was completed, sound edits were made using GarageBand 10.4.8 (Apple Inc., Cupertino, California, United States) while referencing the transcripts. After sound editing, the episode recording was sent to the podcast team (AK, BC, MM, WM, LB, and LAB) to review and provide content and technical feedback. The co-producer (HJ-R) made edits based on the feedback and the podcast was then reviewed by the executive producer (BC) before the episodes were evaluated during focus group discussions and one-on-one (1:1) interviews with PLEX-R.

Video editing and production

Once the sound engineering was completed for each episode, video production began. The co-producer (HJ-R) used iMovie 10.3.5 (Apple Inc., Cupertino, California, United States) to create episode videos. A slideshow was developed for each episode to align with the podcast audio. In general, the slide shows contain the episode number, logo for the Bare Bones Podcast Series, host and presenter biographies, key information (e.g., episode series content), funding, and credits. The videos were reviewed by the podcast team prior to release.

EAT handouts

An EAT was developed for each podcast episode using lay language targeting a Grade 8 reading level. Each EAT contains the corresponding podcast title, key concepts, background information, and recommendations for action, podcast link, and additional resources (Figure 1G). The information in the EAT was presented using a mix of text and infographic information. Multiple Plan–Do–Study–Act (PDSA) cycles (44) were completed to iteratively refine the EATs. This varied from 10–30 versions per EAT.

Podcast episodes and EATs internal review

The project leader and project team reviewed each podcast and EAT for content, clarity, flow, accuracy of the content, and CSCM-CPG content alignment prior to their evaluation by the PLEX-R (Figure 1H).

Bare bones podcast series evaluation

PLEX-R were recruited from a tertiary SCI rehabilitation center in Toronto Canada (Lyndhurst Centre, UHN) (Figure 1I). We intended to recruit 8–10 participants per evaluation block. The consenting PLEX-R reviewed a block of three episodes and related EATs. The participants spent 1 hour reviewing the three podcasts and the three related EATs prior to participating in either a focus group or 1:1 online interview. The focus group and interviews were conducted with three different groups of PLEX-R on three separate occasions with iterative edits throughout. During the focus group meeting, the EATs were shared on screen with the PLEX-R through Zoom's screen share function. The focus groups were conducted by the project leader, project coordinators, a PLEX-P (LB), and two to five consenting reviewers. The focus groups lasted 60–90 min and took place through Zoom (Zoom Video Communications Inc., 2016). Each meeting was opened with introductions, a short project overview agenda, and quick overview of Zoom functionality. The focus group meetings were conducted using a semi-structured interview guide that included qualitative open-ended questions and closed questions to identify trends in terms of (1) design, structure, and format; (2) terminology and word choices; (3) presentation of key concept; (4) action items and take-home message; (5) cultural-linguistic acceptability; and (6) knowledge translation as well as to assess PLEX-R knowledge pertaining to the material discussed (see Supplementary Material: One-to-One Interview and Focus Group Meeting Guide).

The 1:1 interviews were conducted by a PLEX-P (LB) using Zoom. The interviewer received training by conducting a mock interview with an experienced research coordinator who was not involved in the project. Interviews were 30–60 min in length and used the same questions as were posed in the focus group meetings.

All PLEX-R received a gift card and thank you note for their contributions to the project after their the focus group or 1:1 interview participation.

All focus group meetings and interviews were recorded and recommendations were summarized for the project team to review. The project team thoroughly examined and discussed the recommendations from the PLEX-R, aiming to delineate common patterns and identify novel ideas within each group and to summarize overarching observations.

Feedback collected from PLEX-R was used to identify unclear content in the podcasts and EATs and to clarify preferences for the visual formatting of the EATs. This informed substantial revisions to the EATs, as well as to the podcasts and dissemination plans.

Final edit

The podcast episodes were finalized and the EATs were converted to pdf files to upload on to the project website (Figure 1J).

Website and podcast episodes and EATs dissemination

Website development began as a team brainstorming session and a subsequent website framework was created. The website was envisioned as a repository of SCI bone health information, which would include the podcast and other resources. The project team then reviewed other health-related podcasts and associated websites, to further refine the website framework and develop a preferred design based on esthetic feedback and functionality. Website building platforms were investigated. WIX is regularly listed as one of the top three website building platforms and it had the functionality to accommodate the features outlined in our framework for a reasonable fee, specifically YouTube videos, audio streaming, PDF downloads, website analytics to track use, and Google search engine optimization (SEO), which would enable the podcast to appear in Google search results. WIX online tutorials and video training resources helped guide website design and production (45, 46). The domain name www.scifragments.ca was selected, purchased, and connected to the WIX site (Figure 1K).

Once the podcast episodes were prepared and ready to release (audio and EATs finalized and accompanying slide show created), a YouTube podcast was created. Online YouTube tutorials guided this process (46). As a YouTube podcast, the audio content is available on YouTube Music, while the videos are also available on a YouTube channel. The videos, download links for the EATs, and links to YouTube Music were then added to the website.

Survey Monkey was used to create Feedback Questionnaires. Survey Monkey provides guidance on survey creation (47). The survey links were added to the website to collect users' feedback and to assess users' knowledge pertaining to the material discussed in the podcast and EAT. The survey questions were designed to ascertain the following information:

(1) Are end-users absorbing key information? (Can they identify and report back specific key learning objectives?)
(2) How likely are PLEX to incorporate material from the EAT/podcast into daily life or use it to self-advocate with their healthcare team? If yes, how often?
(3) How likely are PLEX to share the EAT/podcast or its learnings with others (family, caregivers, healthcare providers)?

The final component of our website development was the addition of Google Analytics to track use of the website. Google's Analytics Academy training program provided the necessary training to understand and implement Google Analytics on the website (48). While WIX does have analytics features built into the platform, Google Analytics is more comprehensive.

Results

Bare Bones Podcast Series

As mentioned previously, nine podcast episodes and related EATs were designed and created collaboratively with the 3 PLEX-P, 22 PLEX-R, and 11 members of the CSCM-CPG expert panel and the project team (Table 1). Based on the feedback from PLEX-R, Episode 8 was divided into Part 1: Warning Signs of Fracture & Fracture Management and Part 2: Rehabilitation & Osteoporosis Therapy after a Fracture. Each podcast episode was 8–15 minutes in length. Related EATs were one page per episode for Episodes 1–4, 6, 7, and 9. Episode 5 (Calcium and Vitamin D) was two pages based on PLEX-R feedback (See next PLEX-R feedback section). Episode 8's EAT was created for Part 1 and Part 2 separately (Table 2).

TABLE 1 Summary of project team and collaborators.

Group	Role (initial)
Project team ($n = 7$)	Executive producer (BC)
	Podcast co-producer (HJ-R)
	Podcast co-hosts (AK and WM)[a]
	Content project team (LB, WM, AK, and MM)[a]
	Evaluation team (LB and MM)[a]
	EAT creators (MM, BC, and LAB)
	Website producer (LAB)
CSCM-CPG expert panel ($n = 11$)	Podcast guest speakers
PLEX-R[b] ($n = 22$)	Podcast episode and EATs reviewers

[a] AK, WM, and LB are PLEX-P.

[b] PLEX-R were PLEX reviewers who were recruited from the local outpatient clinic.

PLEX-R feedback and podcast and related EAT revision

Altogether 31 PLEX with chronic SCI/D living in Ontario consented to review the podcasts and EATs and participate in either a focus group meeting or a 1:1 interview. Nine of the 31 withdrew their consent due to medical reasons or time pressures. A total of 22 PLEX-R were engaged in the review process of whom 17 were men and 5 were women. The PLEX-R included individuals with paraplegia, tetraplegia, and high tetraplegia and those who walk or use a wheelchair for household and community mobility. The number of unique focus group participants or 1:1 interview participants is provided in Table 3 as the episodes and EATs were bundled for review. The feedback on the podcast episodes and related EATs and the associated revisions are summarized in Table 4. The Supplementary Material (EAT Diagram) shows the EAT diagram created based on PLEX-R feedback.

Podcast and EAT dissemination

We disseminated the finalized podcast and related EATs online from the project website (https://www.scifragments.ca/barebonespodcast) and announced the dissemination in person at the Academy of Spinal Cord Injury Professionals (ASCIP) meeting on 5 September 2023. The Bare Bones Podcast Series was introduced during the presentation. Three-hundred magnets including the project website and common sources of dietary calcium were distributed at the North American Spinal Cord Injury Consortium (NASCIC) booth at the conference. The project X account (@SCIBare Bones) was created to provide a venue to share and discuss our podcast episodes and EATs and bone health–related information and events with patients and family caregivers and several networks including PVA, Spinal Cord Injury Research Evidence (SCIRE), PRAXIS, and the Ontario SCI Alliance and the informal networks of each CPG panel member. We have posted a survey for ongoing feedback regarding the EATs and podcast episodes.

Discussion

This project aimed to co-develop and disseminate a series of nine educational podcasts and related EATs, in a series

TABLE 2 Summary of Bare Bones Podcast episodes.

Episode No.	Episode title	Take-home messages	Episode length	CSCM-CPG chapter
1	Introduction to the Bare Bones of Bone Health	Knowledge is power. See the complete picture for healthy bones and a healthy life.	10:49	Not applicable
2	Fractures: 101	Know your fracture risk. Act to change modifiable risk factors.	11:32	1. Medical History, Assessment of Fracture and Fall Risk
3	Blood Tests: A Window Into You	Get a blood test to learn about your bone health.	7:26	2. Laboratory Screening
4	I See Your Skeleton	Get your knee region bone density test on a regular basis to monitor your bone health and your fracture risk.	13:40	3. Bone Density Testing with Dual-Energy X-ray Absorptiometry 4. Volumetric Bone Density and Bone Architecture: Peripheral Quantitative Computed Tomography and Quantitative Computed Tomography
5	Vitamin D for All, Calcium for Some: Bones, Groans, and Stones	Follow our doctor's advice to get sufficient amount of dietary calcium and vitamin D supplement.	12:37	5. Calcium and Vitamin D3: Diet or Supplements
6	Get Moving and Loading	Exercise is good for you, but passive standing and electrical stimulation-based activities can increase bone health in your legs.	14:48	6. Rehabilitation Therapy
7	Pills or Poisons, and Atomic Habits	There are drugs available to prevent and treat bone mineral density decline. Talk to your doctor about the best drug for you.	14:58	7. Drug Therapy
8 part 1	Snap and Crack Part 1: Warning Sign of Fracture & Fracture Management	Know the warning signs of fracture and seek urgent care from an orthopedic surgeon.	15:32	8. Fracture Management
8 part 2	Snap and Crack Part 2: Rehabilitation & Osteoporosis Therapy after a Fracture	If you have a fracture, get advice from your rehab team to restore your functional independence and to prevent future fracture.	9:55	
9	Directions for Future Research	Consider partnering with researchers to reduce fractures.	11:46	9. Directions for Future Research

TABLE 3 Summary of PLEX-R participants of focus group meetings and one-to-one meetings.

Group	Reviewed podcast	PLEX evaluators (men = 17, women = 5, Total $n = 22$)
	Episode and EATs	
1	1, 2, and 4	Focus group, $n = 4$
		1:1 interview, $n = 4$
2	3, 5, and 6	Focus group, $n = 4$
		1:1 interview, $n = 5$
3	7, 8, and 9	Focus group, $n = 2$
		1:1 interview, $n = 3$

titled "The Bare Bones Podcast Series". Nine podcast episodes and related EATs were designed and created collaboratively with the project team including three PLEX partners (PLEX-P), local PLEX reviewers (PLEX-R), and members of the CSCM-CPG Expert Panel. The Bare Bones Podcast Series was disseminated through the project website and promoted at scientific conferences and through a social media campaign.

In the present project, PLEX-P contributed, collaborated, or were empowered to do the following: (1) participate in grant development and the funding application; (2) identify and refine the podcast titles, opening taglines, key concepts, and take-home messages; (3) schedule and organize planning meetings for guest speakers; (4) host podcast episodes and direct the discussion for each podcast episode; (5) contribute to the creation interview guides; (6) conduct focus groups and 1:1 interviews with PLEX as interviewers; (7) review each podcast episode and EAT for flow and clarity; (8) provide advice regarding the content and language used and ensure consistency between the content of CSCM-CPG and that of the podcast and EATs; (9) provide feedback on the website structure and content and contribute to the dissemination of ideas; (10) contribute as co-authors for conference presentation and workshops; (11) serve as subject-matter content experts and provide advice regarding the education materials' relevance to others with lived experience.

A total of 22 PLEX-R acted as podcast and EAT reviewers. Project team members collected information regarding how education materials should be structured and delivered. This enabled the project team to discern reviewers' perceptions of the podcast episodes and EATs, their efficacy, and ways to improve our dissemination strategy in an impactful way. Although CPGs are traditionally developed for healthcare providers, they can provide useful information to PLEX, family caregivers, informal and formal caregivers, as well as other members of the public (49).

TABLE 4 Summary of feedback from PLEX-R on the podcast episodes and related EATs and revisions made based on the feedback.

Category	Examples of issues and suggestions	Action taken
Design, structure, and format	Need to orient PLEX to the EAT format and use	Diagram outlining EAT Content was added to the Website (see Supplementary Material: EAT diagram)
	Highlight related episodes within the podcast and EAT to assist users to find more information	Related episodes referred to one another within podcasts and EATs (i.e., calcium and vitamin D intake Episode 5 referred to the lab testing episode 3)
	Requests to visually simplify the EAT in terms of number of infographics and use of color	The color background was simplified in EAT 1–9. Numbers were added to key concepts in EAT 3–9 to help the reader navigate
	Request to re-record podcast interview with a more natural conversation	Podcast episodes 1 and 8 were re-recorded
	Reduce volume of information in podcast and EAT	The EAT 5 was expanded into two pages to reduce volume of information on each page. EAT 4 was simplified with a reduction of a number of infographics used. In EAT 9, the number of key concepts was reduced to two from four
Terminology and word choices	Limit the use of medical terminology and use lay language	The language was simplified in each EAT. Some terms were intentionally not simplified as PLEX-R highlighted to need to use the same language with their healthcare providers (e.g., EAT 3, blood test items)
Presentation of key concept, key action items, and take-home message	Ensure the EAT action items and take-home messages are clear and written in an authoritative voice	The take-home messages were visually emphasized in EAT 1–9. Take-home messages for episodes 5, 8, and 9 were refined
	Emphasize the importance of consulting with healthcare providers before implementing recommendations	The need to consult a regulated healthcare profession were emphasized in EAT 2–9
	Information should be updated when the CSCM-CPG is updated	OFI for future revisions
Cultural-linguistic acceptability	Podcast and EATs are acceptable culturally and linguistically	Translate EATs to other languages as OFI
Knowledge translation	Importance of information shared in the series was identified	OFI during dissemination
	Synergistic benefits of the combination of podcast and EAT were reported	
	Create and distribute magnets or bookmarks to promote the Bare Bones Podcast Series	Magnets and bookmarks were created and are being distributed (e.g., at scientific conferences)
	Present a slide show about the Bare Bones Podcast Series in clinic waiting areas	OFI during dissemination
	Format print EATs as single pages or booklet depending on users' preferences	We are experimenting with distributing EAT booklets or leaflets

OFI, opportunity for improvement.

Bone health education for PLEX

Crack et al. conducted a cross-sectional survey among 138 adults with SCI/D, regarding their knowledge and awareness of post-SCI bone health. Self-reported assessments of bone health knowledge were analyzed. Among Canadian participants, 30% ($n = 42$) believed they had adequate knowledge on bone health, while 70% ($n = 96$) believed their knowledge was inadequate or were unsure. Most participants (73%, $n = 101$) reported being concerned about the risks of low bone mineral density (BMD) after SCI and were interested in learning more about prevention (76%, $n = 105$) and treatment options (78%, $n = 108$) (50). Further, Etingen et al. interviewed 32 US Veterans with SCI/D who had experienced at least one lower extremity fracture in the prior 18 months to describe the patients' pre-fracture knowledge of osteoporosis and bone health, diagnosis and management of osteoporosis, history and experiences with fracture treatment, and post-fracture care and experiences (18). The results suggest individuals with SCI/D may lack knowledge about bone health and fracture prevention, and following fracture, feel unable to resume pre-fracture participation. In addition, individuals with SCI/D reported they did not feel engaged when establishing fracture treatment plans. These results imply that individuals with SCI/D could benefit from education regarding bone health and fracture prevention and management. Topics of interest identified included screening, lifestyle modifications, drug/rehab therapy for low bone mass/osteoporosis prevention and treatment, fracture treatment options, and considerations of subsequent function and participation. The Bare Bones Podcast Series attempts to address some of the articulated needs.

Further, Nayak et al. conducted a systematic review and meta-analysis of the efficacy of quality improvement strategies to improve osteoporosis screening [BMD/dual-energy x-ray absorptiometry (DXA) testing and/or treatment (pharmacotherapy)] initiation rates in the general population (21). The results showed patient education/activation appear to be effective for improving BMD/DXA testing and/or osteoporosis treatment rates in patient populations with recent or prior fracture. For populations that include individuals without prior fracture, the results indicated that patient self-scheduling of DXA appears to be an efficacious strategy to increase DXA testing rates. The results of this systematic review among the able-bodied population reinforces that patient education is likely a beneficial strategy to improve osteoporosis screening and/or treatment rates for the SCI/D population.

Podcast and EAT development

Our patient education materials have three main strengths: First, we created evidence-based patient education materials. The podcast and related EAT content were based upon the CSCM-CPG for healthcare providers, which was developed based on evidence that was systematically and scientifically obtained. Second, the podcast and related EAT were co-designed and developed collaboratively with researchers, PLEX, members of the CSCM-CPG panel, and the project team to ensure the materials were adapted to the specific needs and perceptions of the PLEX while ensuring rigorous content. Further, pairing of the audio podcasts and provision of the visual EAT uses two different forms (i.e., audio and visual formats) so that PLEX can choose to use one or both formats to aid their learning and reinforce their recall of the material. These EATs are freely available through the project website, and may be shared freely; however, permission is required to alter them.

1. Evidence-based patient education materials

Health information that lacks quality evidence is unlikely to produce the desired health benefits and may have adverse effects on health outcomes (51). Unfortunately, the general public lacks the skills necessary to distinguish evidence-based resources from those that are not trustworthy (52). The EATs were derived from the information within the CSCM-CPG, which was derived from a series of systematic reviews or narrative reviews based on a comprehensive search of the latest evidence and collaborative synthesis of the related data within the CSCM-CPG panel, the International Society of Clinical Densitometry position statement lead, and the Orthopaedic Trauma Association Delphi consensus lead to align recommendations where feasible. To help users understand that the Bare Bones Podcast Series is credible, the first page of the project website has a brief statement asserting that the Bare Bones Podcast Series is based on the content of the CSCM-CPG and provides the CSCM-CPG link for sharing with one's healthcare provider. Users can visit the expert page listing within the website so they know who contributed to the project and approach local experts where feasible. Episode 1 of the podcast outlines the CPG definition, purpose, and development processes in a simple language to help the listener understand that the Bare Bones Podcast Series content was developed based on the CSCM-CPG recommendations.

2. Co-designed patient education materials

Patient educational materials are often developed by healthcare providers and hence potentially miss important information needed for end-users. To address this issue, we co-designed the Bare Bones Podcast Series and developed patient education materials (i.e., podcasts and EATs) with PLEX to ensure their relevance and effectiveness. Among the multiple strengths of our podcast development process described earlier, a noteworthy strength is that the questions asked in each podcast were co-developed by PLEX partners (PLEX-P), and the podcast hosts were also PLEX-P who share similar experiences and life situations with the intended listeners/users. Additionally, during the development of the podcast and EATs, we received feedback from PLEX reviewers (PLEX-R) on the relevant themes and made revisions based on the feedback (Table 4). It was not possible to make every change suggested by PLEX-R as their comments and preferences differed. Therefore, we made revisions to increase knowledge, likelihood of listening/reading, and reduce barriers to learning about bone health and fracture management considering common themes or patterns to the PLEX-R feedback. For example, some reviewers suggested simplifying the name of the recommended blood test items in both podcast episodes and EATs (Episode 3: Blood tests—a window into you);

while others advocated the use of medical terminology to enable the patient and provider to use the same language when discussing the EATs. Throughout our development process we focused on empowering PLEX to advocate for themselves and encouraged dialogue with their healthcare providers. Thus, we decided to keep the medical terminology regarding necessary blood tests in the Episode 3 but highlighted that patients need to discuss with their healthcare provider to ensure they have all the recommended blood tests.

3. Audio and visual formats of patient education materials

The EAT content was presented using a mix of text infographic and photographs. In the past, paper brochures or pamphlets of patient education materials have been a preferred method for distributing and obtaining information due to their convenience and availability (37). However, criticisms of brochures or pamphlets have included the use of medical jargon and high literacy level. To improve the usability and impact of text-based information, visual material was included with the text to increase understanding, an approach that is helpful for people with low literacy skills or for whom English is a second language (53–55). The use of infographics is a well-substantiated choice for EAT content. In the field of bone health education, adults aged 50 years and older who evaluated educational brochures preferred the brochures with photographs of people of varying ages (50 years and older), races, and genders, as well as photographs supporting each topic (e.g., calcium-rich foods) rather than the brochures that used simple line illustrations (56). In addition, others have reported that infographics and photographs activate visual and verbal language centers in the brain and achieve more optimal learning (57).

Podcasts are increasing in popularity in the patient education field (58–61). Users can listen to the podcast from our website without downloading them to their own device. Following discharge from the inpatient rehabilitation setting, many adults with SCI/D seek to participate in learning in a variety of settings, and many have to balance the competing pulls of self-care, work, and family time. Podcasts can help to facilitate self-paced learning for PLEX in their down time. Health-related podcasts have been shown to be effective in increasing knowledge and promoting positive health behaviors across a range of topics, including prostate cancer (60), nutrition (58), weight loss (61), and menopause (59). A recent study with able-bodied women aged 40–60 years indicated that story-based podcasts introduced by diverse audiences are an engaging and effective way to learn about menopause and change health behavior. However, positioning health information in the form of narratives may influence patient choice and distract from scientifically validated medical information (62, 63). Therefore, ensuring evidence-based content is also important when developing patient educational podcasts. All our PLEX-R indicated that the two formats (podcast and EATs combined) were helpful to understand key concepts and action items.

This study has some limitations. First, the number of PLEX-R was small and they were all from one region, which may limit generalizability. Second, PLEX-R had chronic SCI/D for periods varying from many months to decades; therefore, their feedback may not specifically reflect the thoughts and feelings of newly injured patients. In fact, a few PLEX-R commented that they could now understand the content easily and recognized the value of the information as they had osteoporosis and had been exposed to therapy. They were unsure if new patients who had not experienced screening, diagnosis, or therapy would understand the information provided and/or use the information effectively. Lastly, there were more comments on EATs than podcast episodes during the focus group meetings. Displaying the EATs on the screen may have distracted/biased reviewers.

Our podcast episodes and related EATs are intended to be living education materials that will be revised periodically. The next phases of the project will be to evaluate listeners' perceptions of the podcast episodes and EATs and their efficacy through the online survey linked with podcast episodes and related EATs on the website. In addition, we have recorded sound bites (including Soundbites for YouTube, X, TikTok) to help spread the podcast content. The website will be promoted via social media accounts (X, Instagram, etc.) of SCI-specific non-governmental organizations (i.e., PVA, NASCIC, SCIRE, SCI Canada, SCI Ontario, SCI-Implementation and Evaluation Quality Care Consortium Praxis, etc.). The podcast series and EATs will also be promoted at PVA and UHN clinical sites and via poster/workshops at the future ISCoS, ASIA, and Canadian Spinal Cord Injury-Rehabilitation Association conferences and during Osteoporosis month campaigns.

Conclusion

The Bare Bones Podcast Series includes nine podcast episodes, and the related EATs were co-designed and co-developed and released through the project website for PLEX to introduce them to the content of the newly published Consortium for Spinal Cord Medicine's Bone Health and Osteoporosis Management CPG. These podcasts are freely available online at https://www.scifragments.ca/barebonespodcast. We anticipate the Bare Bones Podcast Series will aid PLEX, their family caregivers, and healthcare providers to advocate for ongoing bone health screening/assessments and to promote an ongoing dialog with care team members regarding how to prevent fractures and fracture-related morbidity and mortality.

Data availability statement

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

Ethics statement

This QI project was approved by University Health Network's Quality Improvement Review Committee (QI # 23-0548).

This project was conducted in accordance with local legislation and institutional requirements. Participants provided written informed consent for project participation.

Author contributions

BC: Conceptualization, Funding acquisition, Investigation, Methodology, Resources, Supervision, Validation, Visualization, Writing – review & editing, Project administration, Writing – original draft. AK: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Writing – original draft, Writing – review & editing. LAB: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing, Visualization. HJ-R: Conceptualization, Data curation, Investigation, Methodology, Resources, Writing – original draft, Writing – review & editing. LB: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. WM: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. MM: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

BC was the Panel Chair for the Consortium for Spinal Cord Medicine's Clinical Practice Guideline for Bone Health and Osteoporosis Management for Individuals with Spinal Cord Injury or Disease. BC is the Chair of the Canadian Spinal Cord Injury Rehabilitation Association and a Board member of the Ontario SPOR Support Unit Board of Directors and a former member of the Osteoporosis Canada Scientific Advisory Committee. BC receives support from the UHN Foundation as the Cope Family Chair in Spinal Cord Injury Health Systems Innovation.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2024.1340881/full#supplementary-material

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Identifying strategies and related principles supporting a co-design approach in an assistive device service delivery and research platform

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Introduction: Possibilities Project Plus (PPPlus) is a free assistive device (AD) marketplace and research platform for persons with disabilities. The overall aim of PPPlus is to increase access to ADs through an integration of service, research and education. To maximize positive outcomes and reflect community needs a co-design approach informed by guiding principles of Integrated Knowledge Translation (IKT) was adopted, with examination of methods related to Experience Based Co-design. The integrated nature of PPPlus benefits from the use of specific engagement strategies that align with IKT principles to meet project objectives. The extent to which partnership and engagement strategies are specified in the rehabilitation research literature vary greatly and studies that provide information on specific strategies used to operationalize principles are limited. The objective of this manuscript is to provide a description of the co-design approach and the specific strategies that strive to achieve meaningful user engagement. By reflecting on these processes we also report on limitations and strategies for improvement.

Methods: The co-design approach is highlighted through specific project activities including a representative governance structure, ongoing environmental scan and iterative Health Equity Impact Assessments (HEIA). The inherent engagement strategies that align with IKT and co-design principles are described.

Discussion: The most impactful engagement strategies included early engagement of partners throughout all phases, ensuring project relevance across partners through alignment of objectives with complementary aims, using HEIAs to promote equitable outcomes from diverse stakeholders, the representative governance structure beyond individuals with disabilities and caregivers, and the use of experiences and stories to inform development.

Next steps: This examination of specific strategies related to co-design focused on partnership engagement and informed targets for enhancement of the PPPlus initiative. These include being more intentional in developing a more rigorous process for evaluation that includes an assessment of strategies and their impact—especially as related to partner engagement. In addition, ongoing and enhanced efforts will focus on developing knowledge products that bring to life the most salient experience-based user stories emerging from the environmental scan with these being used to drive distinct co-creation events as well as serve other knowledge mobilization purposes (i.e., supporting policy change).

KEYWORDS

co-design, integrated knowledge translation (IKT), engagement, assistive device, rehabilitation

Introduction

Persons with disabilities frequently depend on assistive devices (ADs) to enable their independence and enhance their overall well-being (1–3). It is estimated that 2.5 billion individuals world-wide are supported by at least one AD (4). However, there are numerous challenges to the procurement of these essential pieces of equipment such as limited income supports or inequities in service provision. In Canada, funding for devices is not federally legislated, and therefore is a provincial responsibility with many regional inequities and gaps (5). The Possibilities Project Plus (PPPlus) is a free AD marketplace and research platform intended to increase access to ADs (service) and provide evidence to establish the need and methods for enhanced support for persons with disability and their caregivers in accessing ADs in Canada (research). This ongoing initiative serves individuals in Ontario, with eventual plans to expand across Canada, and promote equitable health outcomes with an aim of supporting policy change through evidence.

PPPlus' dual role as a service and research platform, serving as a vehicle for experiential learning, is enhanced through the integration of intentional engagement principles and underlying strategies designed to meet the needs of service-oriented, research and educational partners. The experiential learning approach involved incorporating students from a variety of disciplines throughout various aspects of PPPlus to gain their desired experience while building capacity of the platform.

To maximize positive outcomes for its intended users but also authentically reflect community needs, a co-design approach was deemed integral to the initiative's methodology, effectiveness and sustainability. This approach is further informed by Experience-based Co-design (EBCD) which has roots in Participatory Action Research (PAR) and emphasizes collaboration by involving the active engagement of staff, patients, trainees and other service users in co-designing services and care pathways (6–8). This strategy places significant value on the intentional gathering of user experiences and having stakeholders that are both service providers and end-users play an instrumental role in a shared approach to design, develop and implementation. The flexibility of the EBCD approach was a key advantage to ensure unbiased and specific priorities are identified through the sharing of experiences.

Several researchers have noted the many parallels (or areas of divergence) between various collaborative research approaches such as co-production (i.e., co-design), participatory research or integrated knowledge translation (IKT) (7, 9, 10). In particular, Nguyen et al. (9) demonstrated in an expert-based qualitative descriptive study comparing these approaches with IKT, that many have far more in common than not—with a common thread of the approaches being enabled through "true partnerships" (9). Recently, Gainforth et al. (11) have undergone a series of literature reviews and consensus-seeking activities to identify a core set of IKT guiding principles and related strategies to support quality research partnerships within the spinal cord injury research community (11–14). These guiding principles and strategies were intended to promote collaboration and foster engagement among researchers, policymakers, practitioners, and community stakeholders to allow for services and research findings that are relevant, applicable, and effectively implemented into practice (12). This context specific guidance co-developed with persons with lived experience aims to reduce tokenism in engagement strategies and empower individuals to contribute meaningfully.

These authors used dictionary definitions to signify partnership principles as "fundamental norms, rules, or values that represent what is desirable and positive for a person, group, organization, or community, and help it in determining the rightfulness or wrongfulness of its actions", and strategies as "observable actions designed to achieve an outcome" (13). Although specific strategies are becoming more widely known and used, there is a lack of reporting on the specific engagement strategies associated with co-design or other collaborative research approaches, specifically in scientific articles (15, 16). Furthermore, the extent to which partnership and engagement strategies are described vary widely and studies that explicitly offer insights into the recommended strategies for operationalizing specific principles, particularly the critical aspect of linking principles and strategies are limited (13–15). The absence of such explicit guidance underscores a gap in current research. Reporting and evaluating specific strategies to engage various stakeholders will allow for better understanding on optimal methods for meaningful engagement for specific contexts, thereby enabling adoption of successful co-design and other research partnership approaches. The establishment of clear links between strategies and engagement principles will facilitate teams in enhancing their ability to enact these principles in a practical context (13).

In response to this research gap, the specific purpose of this paper is to describe the co-design approach implemented in PPPlus and the specific strategies designed and used to operationalize IKT principles. These acknowledge diversity and strive for representation and/or inclusivity as well as achieve meaningful research user engagement along with open and ongoing communication. In doing so, we hope to enhance our work toward an effective and responsive AD platform and research hub for persons with disability, with a specific emphasis on promoting equitable access to ADs.

Methods—embedding co-design principles and associated strategies in research activities

Given PPPlus' dual role as both a service and research platform that also serves as a vehicle for experiential learning opportunities, it was important to consider the intentional integration of IKT principles and associated strategies across the various activities of the initiative. Integrating strategies aligned with IKT principles aim to facilitate a cohesive co-design process that (1) engages all service users, (2) includes persons with lived experiences through leadership roles, and (3) enables research to be meaningfully translated into practice and service. The integration of these methodologies emphasizes the interconnectedness of patient-centered research with services, knowledge translation, and collaborative decision-making. These are intended to collectively contribute to the overarching goal of enhancing access to ADs. To illustrate this, we describe three key activities below that were seminal to the development of PPPlus and incorporated specific strategies aligned with IKT and co-design principles as well as identify future adaptations to these strategies. The three key activities include, (1) the formation of a representative governance structure that incorporates multidisciplinary perspectives from the project's inception, (2) ongoing environmental scans conducted across project phases and (3) iterative Health Equity Impact Assessments (HEIA). In this way, the emphasis of this section will address the stated gap i.e., describing the specific strategies we employed to facilitate engagement and co-design and their alignment with IKT principles.

Representative governance structure

From initiation, PPPlus aimed to avoid tokenism, an overarching goal of the IKT principles, where various partners and groups have little say in research/program development by actively engaging and prioritizing perspectives from community organizations, individuals with lived experiences, and service providers (i.e., clinicians and others involved in AD access) to shape project practices. The co-design approach was incorporated in the project's commitment to a representative governance structure that included a diverse array of stakeholders as an intentional strategy involving the intersection of service, research and education. This strategy was embedded from the inception of the initiative which began with a founding partnership involving a community agency bringing together policy and service aims focused on persons with disabilities along with a research team embedded within a specialized rehabilitation centre and aligned with an academic institution. Importantly, the founding partners each brought their primary aims (aligned with their individual missions) to preliminary discussions in shaping the overall objectives of PPPlus such that they were highly relevant and enabled through the inherent strengths and resources of each partner. For example, the community organization has a strong track record in advocacy and enabling social justice efforts for persons with disabilities and has interest in the area of enhancing access to ADs for these individuals. The clinical and research partners shared this interest in ADs from a clinical and service delivery perspective as well as bringing strengths in implementation science and knowledge mobilization. The academic partner was interested in providing their students with experiential learning opportunities across these contexts ranging from involvements in clinical service delivery as well as research ranging from understanding impacts of ADs to informing social justice efforts related to access of ADs.

At the core of this structure is a Leadership team that spans individuals with lived experiences including persons with disabilities, caregivers, clinicians, policy makers, researchers, community partners, and students. This interdisciplinary team meets bi-weekly to deliberate on action items, fostering a comprehensive perspective that enables the IKT principle of shared decision-making.

Supplementing the core Leadership team are specialized working groups, some of which are led by students, focusing on crucial aspects such as marketing, environmental scanning, support agents, website development, risk / privacy, knowledge mobilization, research and evaluation. The student leaders are guided by members from the core Leadership team to direct specific working groups. The inaugural student leaders have been identified through separate projects where they had established their experience. Of note, the community partner brings expertise in policy change and social justice efforts as well as strengths in engagement strategies for persons with disabilities. Two team members from this group have significant expertise in policy/social justice efforts and also bring lived experience with disability which will be increasingly integral to the later stages of this work where we more actively translate research evidence into policy change efforts.

An important component of the strategy is the initiative's inclusion of students from a variety of undergraduate and graduate programs through experiential learning opportunities such that new ideas and diverse perspectives, as consistent with IKT principles, are injected into the initiative while building project capacity, productivity and sustainability as well as providing mentored experiential learning opportunities that facilitate capacity-building across many domains (i.e., clinical insight associated with ADs, service delivery, marketing, research skills, technology development).

Clinicians, including physiotherapists, occupational therapists and a clinical dietician, also play a crucial role within the project team. For example, a critical collaboration involved occupational therapists developing an AD database and determining relevant product specifications. This collaboration supported individuals to access the right products for their specific needs, facilitating enhanced transfers of equipment. Senior hospital leadership associated with the participating rehabilitation centre were also key stakeholders in the initiative. Although not participating in every core leadership meeting, a leadership representative (i.e., rehabilitation program coordinator) was identified and was able to facilitate engagement activities within the organization. In addition to providing a leadership perspective and facilitating clinician involvement, this has proved extremely helpful in leveraging other organizational consultations such as with Risk/ Privacy and Communications Departments.

Another category of strategies that relates to the Governance Structure is reflected in the administrative and logistical supports, aligned with IKT principles of practical considerations, which were inherent in the way the leadership team and working groups operate. An online, inter-organizational, collaborative platform (Microsoft Teams) housed shared document organization, online meetings and discussion boards. In addition, meeting times and frequencies were determined relative to the ongoing team demands to maximize participation. This approach differed in its emphasis on transparency, as all members, regardless of their role and affiliation, were granted access to all materials. Consistent with IKT principles, this not only facilitated transparency but also fostered a culture of inclusivity and collaboration, enabling diverse perspectives to contribute to decision-making processes in an informed manner. Meetings involved having set agendas shared in advance with all involved individuals, recorded minutes and were structured to be as participatory as possible so as to facilitate shared decision-making. A key member of the team involved a staff Knowledge Mobilization Specialist, with experience in engagement of vulnerable populations, who could act as a facilitator to engage team members in discussions as well as in preparation of materials to promote knowledge sharing.

As the initiative matures, and as noted in the environmental scanning activity, additional partners are continually being identified and we are in development of an appropriate structure to ensure their involvement beyond active participation in the existing structures (i.e., Representative Core Leadership team and working groups). This is likely to take the form of an Advisory Team that meets regularly (e.g., quarterly) although an important strategy that governs continuing partnership engagement is that each partnership begins with an intentional series of consultations to identify mutual benefits, concerns and logistical issues along with a terms of reference that outlines expectations for working together. Another key strategy aligned with this is that partnership identification and engagement is iterative and aligned with the overall objectives of the initiative. For example, working group needs are communicated with the environmental scan team, who can then reach out to potential partners with *a priori*ty to explore emerging project needs.

Environmental scan

In order to capture, understand and improve end-user experience and engagement as well as inform overall research objectives we conducted an ongoing environmental scan. The environmental scan involved a single semi-structured interview of approximately 90 min. Initial interviewees were identified through our founding partner who had undergone initial consultations with organizations in the disability community. From here a snowball method was employed where organizations identify other potential interviewees. An extraction template was used to generate a database including organizations' objectives, who they served, and their experience with ADs. The environmental scan specifically focused on Ontario-based organizations and individuals involved in AD distribution, assessment, or procurement, involving online information capture, interviews with organizations and individuals, and an ongoing scoping review. Conducted over the past year, the scan aimed to evaluate the necessity for and provide insights into the development of the PPPlus platform. To date, the environmental scan has involved the capture of online information from 39 organizations, with 12 undergoing interviews to gain additional insights. Moreover, 15 individuals were interviewed individually or in focus groups.

Multiple organizations operate in this domain with similar objectives, however, in a fragmented manner. For example, many organizations from the environmental scan have reported the same issue of having ADs falling into disuse, ultimately ending up in landfills. The scan serves the purpose of identifying and recruiting potential future partners and by employing IKT and co-design principles move towards a coordinated solution, with the ultimate goal of effecting lasting change.

Multiple engagement strategies were used within the environmental scan of PPPlus which enriched the capability to gather information and insights from various perspectives (i.e., patient partners, community members, staff, students, etc.). One strategy used was the targeted recruitment of individuals and organizations through community and professional networks as well as online searches around ADs.

Throughout consultations, individuals would share experiences with ADs, perspectives on the current landscape of AD access and opinions on the need for a free AD platform, enabling the identification of gaps and needs, ensuring that the platform's design and services align with user requirements. Bate & Robert (8) describe stories and storytelling, as the foundation of EBCD, containing essential elements for a profound understanding of the present service and insights into what needs redesign for the future (8). As a result, another strategy was encouraging open sharing of stories and experiences with the interviewee, determining what is important for them to share and avoiding the use of stringent interview guides. By incorporating this narrative-focused strategy, we aimed to capture the individual experiences, recognizing the power of stories to inform and shape our understanding of the patient journey as well as other users or stakeholders related to this part of the healthcare system. Finally, to enable meaningful engagement with stakeholders, another IKT principle, we provide opportunities to explore formal partnerships that can be mutually beneficial. The shared exploration of partnerships allows individuals and organizations to carefully assess their involvement, determine the level of commitment that aligns with their goals, and evaluate whether the partnership is the right fit for them. This strategy facilitates the transition towards a "true partnership". In facilitating a "true partnership", connections between researchers and knowledge users are created throughout the entire research process to guarantee the benefits extend to all parties (9). While acknowledging the distinct contributions of both researchers and knowledge users, there is an equal appreciation for their unique perspectives (9). This marks a departure from situations where knowledge user engagement is confined to consultation or feedback at a specific moment, ensuring that knowledge users have the chance to actively participate in the decision-making process (9).

A fulsome qualitative analysis was not conducted. Rather, following each interview (i.e., which was also treated as an opportunity for facilitating ongoing engagement), the core team reviewed the meeting notes, engaging in collaborative discussions to identify key points of action and plan subsequent steps. The team would then initiate the implementation of these steps, taking into consideration the suggestions provided and assessing their feasibility. As an example, following a meeting with a community organization, a valuable suggestion emerged: to broaden our marketing focus beyond individuals with disabilities to include those who may know someone in need of a device. This suggestion came from an individual, representing an organization, sharing their experiences with trying to expand their organizational reach and the issues they were facing. While this was not formally measured, embracing this recommendation enhanced the scope of our marketing efforts, through identification of additional organizations and individuals.

Health equity impact assessment

Another essential activity implemented in PPPlus is conducting equity assessments using the Ontario Ministry of Health and Long-Term Care's HEIA tool (17). This tool enables the integration of diverse perspectives with a specific focus on promoting equitable outcomes and mitigating any potential unintended negative impacts associated with the development of a platform like PPPlus.

To conduct the HEIA, a large group consensus meeting was organized with 23 participants attending both online and in person, including, students, clinicians, individuals with lived experience, care partners, hospital leadership, software programmers, and other stakeholders. The consensus process took place over the course of a full day. Diverse groups of participants engaged in small group-based discussions consisting of 3–5 individuals. The small breakout groups were structured to ensure there were diverse perspectives in each group (mix of clinicians, students, person with lived experience etc.) bringing together individuals with varied backgrounds and expertise. These discussions focused on addressing a range of equity-related questions. Guided by the HEIA template, the groups explored topics such as identifying affected populations, examining potential unintended negative impacts of the platform, proposing potential solutions and determining areas of priority.

The HEIA template itself played a crucial role by prompting a comprehensive examination of potential at-risk populations. This structured approach required participants to intentionally contemplate how the platform's implementation might impact various marginalized groups. The template guided participants to delve into detailed analyses with thoughtful considerations of social determinants specific to each demographic. By necessitating a thorough exploration of potential risks and impacts on diverse populations, the HEIA template not only encouraged nuanced discussions but provided a systematic assessment of the potential consequences associated with the platform's deployment. The HEIA provided a method for flexible and receptive tailoring of both the service and research as per the IKT principle, by creating risk mitigation strategies.

An engagement strategy operationalized here was the intentional design of small group discussions and subsequent report-back sessions to allow for every participant to have the opportunity to contribute their insights and lead conversations. This structure was pivotal to create a safe environment for engagement as reported in previous literature (15). In addition to fostering a platform for collective dialogue, the consensus process empowered stakeholders through the shared determination of priorities and solutions. This inclusive strategy enabled an open exchange of ideas and opinions, aligned with several IKT principles, resulting in the identification of key themes and priority areas that demand attention, especially concerning potential negative impacts. Actively involving stakeholders in decision-making not only amplifies diverse perspectives but also promotes power-sharing within the initiative, creating a collaborative environment where decisions are collectively driven and facilitating positive engagement (15).

Preliminary findings from this process identified potential adverse consequences associated with the development of PPPlus, including issues related to technological inequity, disparities in digital literacy, shifts in perceived government responsibilities, unnecessary or unsuitable equipment acquisitions, and challenges related to transportation barriers. Furthermore, key sub-populations identified included older adults, individuals with low socioeconomic status, rural residents, and minority communities. In response to the findings gathered thus far, a set of actions to mitigate inequities have been identified for priority impacts as deemed by the group. Among these, the creation of PPPlus Support agents stands out. The support agent roles are taken on by student volunteers supervised by members of the core Leadership team. These agents are accessible both in person and online, providing assistance in navigating the platform and addressing issues stemming from a lack of technology or digital literacy. The training process for the support agents consists of a set of standard operating procedures highlighting various scenarios and expected actions and continues to evolve as the platform grows. This proactive approach aims to mitigate potential challenges and enhance inclusivity within the PPPlus framework.

Summary of strategies related to IKT principles and other collaborative research approaches

As noted earlier, there are similarities between various collaborative research approaches incorporating co-design, although separate literature reviews have shown a general lack of clarity or specificity in documenting specific strategies associated with the operationalization of over-arching principles such as effective ways to achieve representativeness, inclusivity and meaningful involvement of partners (7, 9, 13). Gainforth and colleagues have conducted a series of literature reviews and consensus activities to identify a set of guiding principles associated with one of these collaborative approaches (IKT) (12–14). Hoekstra et al. (18) extended this work by proposing a system—based on the acronym "RECIPE"—that enables characterization of specific strategies in alignment with these guiding IKT principles (18). Table 1 employs an adaptation of this approach to summarize the embedded strategies within our own work in PPPlus involving an integration of service, research and educational activities to enhance access to ADs for persons with disabilities. This table provides an explicit summary of the engagement and co-design strategies we

TABLE 1 Specific strategies employed in PPPlus linked to the IKT guiding principles and "recipe" concept (11–14).

"Recipe" categories	Strategies
• Related IKT principles	
Resources and time • Logistics & practical considerations[a]	• Meetings and engagement activities structures around members schedule's • Multi-faceted approach to provide in-kind or paid support for members • Development of student "agent" team to provide support as needed
Engagement strategies (fostering collaborative/communication processes) • Ensure all voices are heard[a] • Empower community members • Foster shared decision-making and co-ownership/co-production[a]	• Encourage open sharing of stories and experiences rather than structured interview guides with participants (or partners) • Use of targeted strategy to identify and engage organizations and individuals in AD space o Enabled by growing community network through partnerships o Further supported by online searching/environmental scan activities • Shared creation of solutions and identification of priorities • Emphasis on facilitative leadership style across teams
Communication activities & methods • Open and ongoing communication[a]	• Most activities are supported by an online collaborative platform (Microsoft Teams) supporting shared document organization, online meetings and various communications functions (e.g., archived chats and discussion forums)
Initiatives for collaborative activities • Ongoing monitoring and evaluation of collaborative research activities[a] • Facilitate ongoing knowledge mobilization	• Consensus meetings typically include small groups to facilitate comprehensive dialogue and sharing from all perspectives (e.g., HEIA process employed consensus methods involving structured nominal group and break-out groups) • Use of Re-Aim Framework (19) including a process component for ongoing monitoring and evaluation (planned) • Meetings have set agendas, recorded minutes and structured to be as participatory as possible
Partnership representation/relationships • Facilitate relationships based on respect, trust and credibility (avoid tokenism)[a] • Partners involved in any & all phases of initiative (including early) • Ensure research is relevant and involvement of members is meaningful[a] • Co-development of norms, rules and expectations	• Governance structure is representative and organized to facilitate collaboration and member involvement o Identification and supported involvement of "Game-Changers" i.e., innovators that are flexible and promote new ways to work and collaborate e.g., Policy Specialists who also bring lived experience, Senior Administrator leveraging organizational resources, Implementation Scientist, Knowledge Mobilization Specialist, IT Specialist cross-trained in Research Coordination/Project Management
	• Comprehensive strategy (including environmental scan) to identify partners and recruit individuals from different disciplines, backgrounds and sectors o Marketing strategy (including through community partners) targets research participants, some of which may become partners • Core project team and working groups includes members from policy sector, persons with disabilities, researchers, clinicians, students, community organizations • 29 Students support this initiative from various disciplines (Health Sciences, Occupational Therapy, Medical Sciences, Global Health, Business and Computer Science) • Consult with partners and research users collaboratively to agree upon level of commitment and engagement • Involvement of a knowledge mobilization specialist to facilitate collaborative processes
Education and training	• Corporate onboarding available for all members (staff, volunteers, persons with disabilities, students) • Content specific resources created (e.g., AD training package)
Other • Partners address ethical challenges related to collaborative research activities[a]	• Iterative HEIA processes as consensus exercises to identify ethical challenges and sources/solutions related to inequity • Corporate risk and privacy consultation • Routine exploration of issues related to ethics, inequitable access to ADs and logistical challenges in environmental scan and partnership discussions

[a] Related IKT principle (12, 18).

employed, structured to reflect their alignment with Hoeksta et al.'s IKT principles (12, 18). Of note, we also examined methods of EBCD with a view to further enhancements.

Discussion

Co-design methods have become increasingly employed within the design and implementation of research or quality improvement initiatives. These are often a key component of collaborative research approaches that involve meaningful involvement of partners, and although structured processes are often involved, there is a general shortcoming in the literature in reporting the specific methods associated with co-design and partnership engagement or involvement (13–15). In the present manuscript, we were informed by Gainforth and colleagues work that identified a set of guiding IKT principles (12, 18) to more intentionally describe the specific strategies that enabled an integrated research, service and education initiative designed to enhance access to ADs for persons with disabilities. Specifically, we used Hoekstra et al's (18) "RECIPE" system to identify specific strategies that were used in this initiative to enable the co-design approach with a focus on partnership engagement and ongoing collaboration (see Table 1). In examining literature addressing principles and underlying strategies related to collaborative research (including co-design) it is evident there is significant overlapping of concepts and nomenclature. Also, although there is little detailed information on how specific strategies may operationalize principles, this was evident in our own work such that a given strategy may relate to multiple principles. This suggests that one should consider a combination of strategies to bring key principles to life. We also outlined three key research activities (representative governance structure, environmental scan, equity assessment) for this initiative and described how the specific strategies for co-design and partner engagement were implemented within these.

In striving to create and continually improve a service that also incorporated research and experiential learning opportunities for students, we sought to integrate co-design as a fundamental practice, yet also noted the need to establish processes that enlarged the focus beyond gathering perspectives and data limited to only the patient experience (20). Rather, this was enhanced to address all end-users and other stakeholders. Moreover, patients and other stakeholders should not be viewed as mere sources of information but as authentic partners in the process, recognizing their genuine contributions and collaboration (20).

Previous literature highlights the most frequently reported principles and strategies, but within the context of PPPlus, certain strategies stood out as particularly impactful, leading to tangible changes resulting from engagement and informing co-design. This included involving partners in all phases, especially in the early stages, facilitating comprehensive integration where partners could actively contribute to development well before the launch. By doing so, partners were involved in decisions from the project's inception rather than as an 'afterthought' or restricted to consultant roles as often described (9, 20). The partnership with the community organization with experience supporting individuals with disabilities as well as bringing expertise in policy change will be instrumental to the project as this aligns with the ultimate objective of the initiative. This partnership allowed for a synergistic blend of expertise, ensuring that the unique needs and perspectives of the target population were consistently considered throughout development and maintained the commitment to eventually bringing about policy change through social justice efforts. This approach not only prioritized the voices of service and knowledge users but also reinforced the project's broader mission of creating lasting positive change within the community.

Previous articles surrounding engagement approaches that we have encountered have not covered a structured strategy to address ethical concerns or promote equitable outcomes (18). The HEIA used in PPPlus provided a chance for various stakeholders with diverse backgrounds and expertise to intentionally consider how inequities may be perpetuated through this work and actively generate solutions to mitigate this. By continuing to conduct HEIAs and engage stakeholders in this comprehensive process, intentional equity considerations will continue to be at the forefront of the platform's design and promote the representativeness of the involved stakeholders.

This approach empowers stakeholders to contribute their insights and expertise, promoting equity, and enabling the project team to address potential challenges proactively. A fundamental aspect of this framework is that it provides a logical pathway from identifying potential ethical concerns regarding inequities to considering solutions that are grounded in social determinants and perspectives related to marginalized groups. However, recognizing the potential for improvement, future iterations could benefit from more intentional involvement of representatives from specific marginalized groups to further enhance the depth and relevance of the analysis. By continually refining these processes, we aim to maintain our commitment to inclusivity, equity, and the consideration of social determinants in our ongoing efforts to address the needs of diverse populations.

Another important strategy was surrounding the representative governance structure. Often it is individuals with disabilities and their caregivers collaborating in rehabilitation research, especially concerning service delivery where other stakeholders are underrepresented (15). However, other stakeholder groups provided the potential to contribute significantly by leveraging their distinct perspectives and skills. PPPlus recognized the potential of a diverse engagement strategy, partnering with a community organization to expand reach and also engaging important stakeholders from front line clinicians, senior leadership, policy sector and more—boosting sustainability and feasibility. Importantly, by integrating senior leadership from our hospital partner as an active role on the service delivery side, we were able to secure a designated leadership contact. This individual played a crucial role in navigating alignment with the rehabilitation center's goals, facilitating a more cohesive and strategic approach to service delivery. Senior leadership, as well as participation from an operational manager, enabled discussions with the organizational Risk and Privacy department to establish safe practices and minimize liabilities.

Finally, by adapting the traditional environmental scan and information gathering efforts to focus on sharing experiences and stories PPPlus is able to capture a nuanced understanding of one's experiences. In this process, narratives have proven to be catalysts for meaningful discussions, guiding development processes which is an integral part of an EBCD approach, although future efforts may extend this aspect in line with a more rigorous approach to storytelling as part of a more formal co-design event (6, 21). The environmental scan also played a crucial role in enabling the recruitment of specific partners, the identification of strategic approaches to connect with other collaborators and the utilization of various networks to broaden outreach.

In addition to the strategies noted above felt to be most impactful for the context of PPPlus, it is worth noting how these compare with findings from other researchers. In their scoping review, Hoekstra et al. (13) noted that the most frequently reported strategy was having structured meetings (whether face-face, phone or conference calls). We identified this to be useful as well. Heaton et al. (22) reported on a large collaborative initiative conducted by the National Institute for Health Research across England which identified nine core mechanisms characterizing "closer collaboration". In addition to the importance of initiatives being driven by local end-users they noted that having "game-changers" and "facilitative leaders" as part of a small strategic core team are integral to success. "Game-changers" are innovative and find new ways to do work and "facilitative leaders" have real and perceived credibility combined with enthusiasm and perseverance along with a style that encourages partnership involvement. The ability of the team to bring together various partners that represent the requisite "creative assets" is another mechanism. In the PPPlus context, these mechanisms have been instrumental to success as we have brought together innovators ("game-changers") and several facilitative leaders that comprise a rich blend of expertise and knowledge across domains related to policy, implementation science, knowledge mobilization, information technology, administration, experiential learning, clinical subject matter expertise (i.e., ADs) and lived experience.

Overall, the nature of PPPlus as both a service and research platform along with a focus on experiential learning presents a unique need to incorporate research, service and education (i.e., student) engagement strategies. The IKT framework was designed with research partnerships in mind, aligning with other collaborative research approaches (e.g., PAR). On the other hand, EBCD directs its emphasis towards quality improvement and/or implementation related to service. Our overarching objective within PPPlus is on an integration of service and research while providing an experiential education component. Therefore, some principles/strategies are likely to be appropriate, but there may be some oversights or specific strategies that may also be more helpful with these various contexts. This complexity may prompt us to explore alternative considerations and strategies that can enhance our multifaceted approach where these approaches may not fully serve one context or another. A significant challenge for our own work lies in this complexity and the need for a broad representation and diverse skill sets and perspectives to be included in the various engagement and co-design strategies. For those planning collaborative approaches involving co-design, an important consideration is to think about the overall context and objectives of the initiative and consider those strategies that seem most likely to link with the desired principles but noting that it all starts with meaningful engagement and a shared vision from the outset.

Limitations

The co-design approach implemented by PPPlus, while informed by various engagement strategies, is not without its limitations. Three key challenges are evident, namely the time-consuming nature of the process, difficulties in fully representing all relevant stakeholders, and balancing the engagement strategies of service and research along with involving an experiential learning component.

The co-design approach, with its emphasis on engaging multiple stakeholders and incorporating iterative feedback loops, is inherently time-consuming. The thoroughness of the process demands a significant investment of time and resources. The challenge lies in balancing the need for a comprehensive co-design with the urgency of addressing the immediate needs of individuals with disabilities. The dedication of organizational time and resources to this process is substantial, and there may be inherent tensions between the thoroughness of co-design and the pressing demand for timely solutions. PPPlus aimed to address this by leveraging an experiential learning model where students are able to gain experience they are interested in, while supporting the PPPlus through specific working group tasks.

In addition, despite efforts to engage a diverse range of stakeholders, including individuals with lived experience of disability, caregivers, clinicians, policy makers, researchers, community partners, and students, the challenge of fully representing all stakeholders persists. Hard-to-reach groups, often marginalized or facing barriers to participation, may not be adequately represented in the co-design process. Persons with disability often face significant barriers to participation with challenges often associated with transportation, limited energy and having to manage secondary health complications. The engagement process undertaken aimed to be as accessible as possible following the schedule of our partners, offering online or in person engagement sessions/meetings and communicating with them in their preferred way. This is accomplished through intentional conversations with all stakeholders. It's essential to acknowledge that the inability to include all groups thoroughly due to various constraints does not render the co-design process irrelevant, nor should it be a reason to delay action. The co-design process should be viewed as iterative and open to improvement over time. Implementing agile principles can help mitigate time constraints by allowing the project team to respond to changing needs, reprioritize tasks, and iteratively build upon previous work in a more flexible manner. While it may not be possible to reach out to every potential stakeholder or impacted group in the initial stages, ongoing efforts to expand representation should be an integral part of the project. Feedback from the initial stages can inform strategies for reaching and including hard-to-reach groups in subsequent iterations.

Finally, PPPlus functioning as both service delivery and research requires use of engagement strategies related to both domains, in addition to offering experiential learning opportunities. Given this, engagement approaches may not have been entirely applicable to each aim resulting in a potential impact of less than complete adherence to respective processes that were intended to target each area. It will be crucial to continue evaluating and determining what works best across this integrated context.

Conclusions/next steps

The co-design approach adopted by PPPlus is characterized by engagement and partnership strategies aimed to align with principles consistent with IKT with additional linkages to methods associated with EBCD. These strategies are highlighted through three key activities, a representative governance structure, ongoing environmental scan, and iterative HEIAs to achieve overarching IKT principles of acknowledging diversity, striving for representation and/or inclusivity, creating meaningful research and service user engagement and fostering ongoing communication.

In response to the current discourse on engagement within the rehabilitation setting, there is a growing need for heightened transparency regarding specific strategies that operationalize these fundamental principles. The present manuscript attempted to address this need by detailing specific engagement strategies and demonstrating their relationship to specified principles that enable co-design associated with an integrated service, research and educational initiative. However, there is still a need for guidance regarding the specifics of reporting and the details to best operationalize principles. The field would benefit from development of a standard reporting framework, although we believe the "RECIPE" approach suggested by Hoekstra et al. (18) is a useful step in that direction.

Going forward, we plan to intentionally evaluate the effectiveness of the engagement strategies by employing process and impact evaluations informed by the RE-AIM Framework (19) and also focused on the perspective of our partners and adapting strategies accordingly. Importantly, we underscore the significance of comprehensive reporting on limitations, recognizing that this transparency is essential for adaptive strategies and future planning of other studies and projects. By acknowledging limitations, PPPlus aims to foster an environment conducive to continual improvement and innovation in the pursuit of effective engagement and partnership in the rehabilitation context.

Drawing from EBCD frameworks more, a shift towards more intentional narrative driven co-design events to maximize impact and broader involvement is another approach that we intend to conduct. The significance of user stories and experiences in the EBCD process can be captured during workshops or individual interviews and disseminated to those engaged as well as to future stakeholders which will further establish needs and ensure seamless continuation of a transparent co-design process. This will likely include exploring diverse knowledge dissemination strategies involving stories to enhance the co-creation of events but also serve as the foundation for the policy change.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Author contributions

TJ: Conceptualization, Investigation, Methodology, Project administration, Writing – original draft. JE-K: Conceptualization, Investigation, Methodology, Writing – review & editing. AS: Conceptualization, Investigation, Methodology, Writing – review & editing. DW: Conceptualization, Investigation, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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A co-design process to develop personalized mobility programming for individuals with mobility impairments

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Introduction: Individuals with neurological conditions (e.g., stroke, spinal cord injury, multiple sclerosis) may experience challenges to their mobility. While the individual needs for persons with neurological conditions may vary, thus making intervention development more difficult, identifying key personalization or tailoring variables may help to customize interventions. However, the process to personalize treatments has not been well described. It is also unclear how adaptive intervention design includes the perspective of those with lived experience. Co-design methods may be a way to be transparent about intervention development to meet the needs of persons with mobility impairments while ensuring the resulting intervention is relevant and applicable to those who will be participating. The purpose of the present article is to describe a co-design process to facilitate the development of personalized mobility programming for persons with mobility impairments.

Methods: Development of a set of personalized mobility programming for individuals with mobility impairments was conducted following an adaptive intervention design approach with a co-design component. A series of working groups and individual sessions with key interest groups (e.g., persons with lived experience, fitness instructors, front-line clinicians, students) were conducted in order to develop the personalized mobility programming based on the needs and preferences described during various working groups.

Results: Two sets of working groups and three individual one-to-one sessions were conducted with a total of 14 participants ($n = 6$ persons with lived experience, $n = 4$ research team members, $n = 2$ physiotherapists, $n = 2$ occupational therapists, $n = 1$ registered kinesiologist). From the information gathered during the working groups a set of four personalized mobility programs were developed: (1) cognitive cardio class, (2) functional strength class, (3) mobility circuit group, and (4) an open gym. Participants also discussed the onboarding process, how to effectively track participant goals throughout the programming and personalization variables.

Discussion: The current paper provides a guideline for future work that aims to develop programming that is personalized to the needs of the persons with mobility impairments due to various neurological conditions. The strengths of this approach include the collaborative nature of the program development, while the main limitations were logistical in nature (e.g., scheduling, engaging all working group members).

KEYWORDS

adaptive intervention design, co-design, integrated knowledge translation, mobility, neurological conditions

1 Introduction

Individuals with neurological conditions (e.g., stroke, spinal cord injury, multiple sclerosis) may experience a variety of health concerns, including issues with mobility. The mobility needs of this population require specific programs to address mobility related concerns. However, the needs of individuals within this population can vary greatly, which makes it challenging to create a single intervention that meets the unique needs of each participant. One approach is to identify *personalization* or *tailoring* variables, which are participant attributes that are used to customize the intervention. The process through which these personalization or tailoring variables are developed in practice is not well understood. A recent systematic review by Malmartel et al., 2021 (1) aimed to classify the methods that have been used to personalize participative interventions in randomized controlled trials. With respect to personalization specifically, the authors identified that 72% of protocols that met their inclusion criteria failed to adequately describe what tailoring variables were used in the included interventions (1). The lack of transparency throughout the currently available literature makes the development of future trials more difficult and calls into question the validity and applicability of resulting interventions for their target populations. One approach that may help to provide a transparent process while maintaining clinical significance is an adaptive intervention design.

Sequential, Multiple-Assignment Randomized Trials (SMARTs) support the development and evaluation of a sequential, individualized, multicomponent intervention which accounts for the changing needs of participants over time (2, 3). What is unique about this type of adaptive intervention is the consideration of multiple decision points over time, which are meant to tailor and individualize the intervention (2). There are four main components of adaptive intervention design: decision points, tailoring variables, intervention options, and decision rules (2). Traditionally, a treatment package method is used to develop these multicomponent interventions, followed by a randomized controlled trial to evaluate the performance of the intervention (2). However, this process does not allow for the investigation of the performance of the specific components of the treatment package (2). In order to ensure that each of the components is effective, the Multiphase Optimization Strategy (MOST) framework has been suggested (2). This framework is used to optimize and evaluate multicomponent interventions (2). MOST has three phases: (1) Preparation, (2) Optimization and (3) Evaluation. In the Preparation phase, information is gathered from currently available literature, clinical experience and other sources to develop a theoretical model (2). In addition to the development of the model, the Preparation phase is where the optimization criteria is selected (2). In the Optimization phase, decisions regarding which components meet the optimization criteria are made. Finally, the resulting intervention is assessed during the Evaluation phase (2). Unfortunately, studies that utilize the MOST framework often fail to describe the optimization and preparation phases. For example, a recent systematic review found that of the 58 articles that indicated they used the MOST Framework, there was considerable variability in how the other elements of the MOST framework such as the preparation stage were described (4).

While the MOST framework describes an important process that can help enhance intervention science, it is unclear about how persons with lived experience (PWLE) should be involved in its activities. There is substantial work in the field of integrated knowledge translation (iKT) that highlights the importance of collaborations with PWLE and other key interest groups (e.g., researchers, clinicians, representatives from SCI/D community organizations and funding agencies). One primary example is the work in spinal cord injury/dysfunction (SCI/D). The iKT guiding principles were developed by a multidisciplinary group of key interest groups described above to ensure that SCI/D related research is relevant, useful, useable, and avoids tokenism (5). Tokenism is defined as when the research users are asked to join a research project, but have little control or involvement in its construction (6). The work of this group includes strategies that fall into six categories: (1) resources and time; (2) engagement strategies in the research process; (3) communication activities and methods; (4) initiative for collaborative meetings, conferences, and/or events; (5) partnership initiation and representation; (6) education and training (6). It is through these strategies that researchers can avoid tokenism, and ensure the products are applicable to the target population.

Taken together, an adaptive intervention design that integrates the iKT guiding principles can help to ensure that meaningful engagement for key interest groups in the development of personalized mobility programming (PMP). This is what is known as a co-design approach. Co-design uses a pragmatic and inclusive research strategy, where PWLE work directly alongside researchers, clinicians, trainees and data scientists to provide iterative progress toward intervention and trial development (7).

From an adaptive intervention design perspective, adopting a co-design approach can facilitate the development of a set of mobility programming by ensuring that the resulting programs are relevant to the target population. Furthermore, key tailoring variables that are required to personalize the intervention to the individual participants can be developed due to the involvement of all key interest groups (e.g., PWLE, researchers, students, fitness instructors, clinicians). The co-design process typically involves qualitative approaches (e.g., interviews or focus groups) and the formation of a working group, to ensure that the experiences of the stakeholders are captured (8–13). While it is well understood that capturing the experiences of PWLE and other key interest groups is vitally important to developing high quality, relevant and ethical research, the actual involvement of this group outside of "traditional" qualitative work in the development process is seldom described in detail. Therefore, it is the purpose of this paper to describe the co-design process undertaken during the Preparation and Optimization phase (hereby known as pre-research activities) to develop a set of PMPs and the tailoring variables using an adaptive intervention design approach. For the purposes of this work, the intervention will be the resulting PMPs.

2 Methods

Prior to the main research trial, we embarked on a developmental process utilizing a co-design approach. In order to develop the interventions, the MOST framework was followed (2). The Preparation phase of the project involved three formal information gathering activities: (1) environmental scan (e-scan) of current available programs; (2) interviews with PWLE regarding their involvement in mobility programming; and (3) interviews with clinicians and fitness instructors who have participated in the development or running of mobility programming. The findings from these activities will be described in future publications. This phase also involved a co-design process to inform a set of PMPs, which included determining the key decision points required to tailor the programs to meet individual needs (e.g., criteria to be eligible for participation, criteria for modifications, etc.). For the purposes of this paper, the process is described in a linear fashion, however, information gathering activities happened concurrently with program development and trial design activities. According to institutional guidelines, this was deemed a quality assurance initiative, therefore formal ethical approval was not required.

2.1 Co-design process

The development of the PMP was facilitated by the involvement of key interest groups including PWLE, fitness instructors, clinicians, researchers and students. With the intention of incorporating feedback of these key interest groups throughout the project, two working groups were set up that were facilitated by research staff. The first working group consisted of PWLE, fitness instructors, researchers and students. The purpose of this group was to develop ideas that could be translated into mobility programming to inform a pilot trial as part of the Preparation phase of the MOST framework (pilot trial will be described in future publications). In addition to program development, the first working group was responsible for identifying key decision points that would be used to determine which programs participants would be involved in and how those programs could be personalized to meet participants needs. The second working group consisted of clinicians working in the rehabilitation hospital (i.e., occupational therapists and physiotherapists). The second working group was asked about the developed programs including their feasibility and specific tailoring variables from the clinical perspective. In these ways, the co-design process helped to ensure that the two key components of adaptive intervention design were met (developing feasible and evidence-based programming and identifying key tailoring variables). In addition to the working groups, three one-to-one sessions were held, two with an additional clinical staff member and one with an individual with lived experience to review the PMPs that were developed.

In alignment with the iKT principles "RECIPE", we utilized a number of strategies to ensure meaningful engagement (14). The following are examples of strategies undertaken: (1) *Resource & Time (R)*: Working groups were held virtually or in-person depending on preference; (2) *Engagement strategies in the research process (E)*: Working group members were asked to provide feedback at all stages of the development process, including the development of the interventions. Working group members were asked to provide feedback during sample classes in order to ensure that the research team captured the key aspects of programming that they working described as important; (3) *Communication activities and methods (C)*: Emails were sent to all working group participants following the sessions with the meeting notes. Working group members were asked to review the notes and provide any feedback on what was discussed during the meeting if they did not feel comfortable in the group setting. (4) *Initiative for collaborative meetings, conferences, and/or events (I)*: In addition to being able to email feedback if working group members were comfortable in the meeting, the facilitators of the working group aimed to ensure everyone had the opportunity to comment before moving on to the next question. This included directly asking specific members if they had anything to add. Furthermore, during the analysis of the data, we treated all ideas equally, ensuring that the loudest voice did not drive the development of programming; (5) *Partnership initiation and representation (P)*: Individuals were asked to participate in our working group if they had previously participated in mobility related programming at our institution. An initial meeting to discuss what the working group would entail, frequency and expectations was conducted with each potential group member. We aimed to ensure representation for a number of key interest groups including PWLE, clinicians, fitness instructors and research staff; (6) *Education and Training (E)*: Prior to the first working group, members were provided with information regarding what mobility programming was already available at our institution, to help facilitate discussions about what was missing.

2.1.1 Working Group Members

Individuals with experience in either participating in or facilitating mobility programming at a large research hospital in an urban area were invited to join the first working group. The members of the working group consisted of five PWLE (e.g., persons with multiple sclerosis, spinal cord injury, brain injury), five fitness instructors, and four research team members (e.g., staff, trainees). Several of the working group members fell into multiple categories (i.e., PWLE who taught fitness programming at the rehabilitation hospital). In total, eleven individuals contributed to the first working group. To participate, individuals must have been able to join one working group session per week via Microsoft Teams.

For the second working group of clinicians, members must have had experience administering or developing mobility programming. Four individuals who were working as clinical staff at a large rehabilitation hospital participated in the second working group ($n = 2$ occupational therapists, $n = 2$ physiotherapists), and a registered kinesiologist and PWLE (i.e., individual with stroke) participated in individual sessions. Members of the second working group were asked to participate in one session via Microsoft Teams.

2.1.2 Structure

2.1.2.1 First working group

Each session was run using a focus group format facilitated by research staff. Sessions were held virtually or using a hybrid format. Two members of the research staff were responsible for facilitating discussion, while one additional staff member was responsible for notetaking. A focal prompt (main topic of discussion) was provided to working group members, who provided their insights and thoughts while a research staff member wrote down participant ideas on a Microsoft Word document while sharing their screen. By employing a visual display and providing real-time notes, this method effectively promoted discussions among members of the working group by enabling them to observe and listen to each other's contributions. This process was adapted from Concept Mapping procedures where a focal prompt is used to develop a list of statements regarding a specific topic (15).

The first working group session involved an introduction to the working group goals, as well as an overview of the findings from the information gathering activities described above. Decisions on what would be discussed in subsequent working group sessions were decided by the leadership team (e.g., PWLE, research staff). This was an iterative process that included developing focal prompts based on the previous weeks discussion in the working group (see Table 1 for session focal prompts).

2.1.2.2 Second working group & one-to-one sessions

In the second working group, research staff introduced the clinicians to the programs that were developed (i.e., circuit group, cognitive cardio, functional strength training and open gym) and asked about the feasibility of the programming. The clinicians were also asked about key decision points for inclusion/exclusion in each of the programs, when modifications would be needed and when participation in a program should be stopped.

Two sessions were held with a clinician who was unable to attend the first or second working group sessions. The first session was a one-on-one meeting where the individual was provided with a high-level overview of the research conducted to date and an introduction to the prompts given to the working group members. The second meeting included undergraduate students who provided additional questions and prompts as needed. In this meeting, the individual was asked questions pertaining to PMP structure, key decision points and considerations for developing a novel triage system, potential exercises and activities that could be implemented in the program, the advantages and disadvantages of virtual and in-person delivery models, and the feasibility of programming for the patient populations and participants they work with. In the one-to-one session with the PWLE facilitated by the core research team, the member was asked about their thoughts on the triage process and the developed programs.

Following each of these sessions, the core research team and undergraduate trainees analyzed and implemented the feedback provided by each of the groups into trial documents and processes.

2.1.3 Program development via co-design

The programs and associated tailoring variables were developed based on the information gathered during the working group sessions as well as information from the information gathering activities (e.g., qualitative interviews, e-scan). Following a review of the first four brainstorming sessions, a list of potential programs was created (e.g., functional strength training, cardio). In addition

TABLE 1 Focal prompts for working group brainstorming sessions.

Session number	Focal prompt(s) for each session
1	Introduction to working group activities What components should be included in personalized mobility programming?
2	If you were a new participant, what would you like to happen during the onboarding process before you start? If you were a fitness instructor starting a new program, what information about the participants would be most useful to have prior to beginning?
3	What programs, outside of what is already available at the rehabilitation hospital, would you like to participate in?
4	How would you like to be able to gather information about programs at the rehabilitation hospital?
5	Program trial #1 – Cognitive cardio
6	Program trial #2 – Functional strength training
7	What would the triage process look like when wanting to join one of the identified programs?
8	What would the check-in/feedback process look like for each of the identified programs?

to the development of brand new programming, the current programs available at the rehabilitation hospital were also reviewed and included if they met the needs described by the working group. Members of the research team with expertise in mobility program development worked to create the programs to be used in the pilot trial (described elsewhere). In order to test the programs developed by the research team, a trial class was conducted with the working group. The trial classes consisted of an introduction to the class, including a description of the purpose, a 10–15 min trial, followed by explanations about what the full class would consist of. Following the trial, the working group was asked about their thoughts about the program. This included if the group felt that the class was representative of previous discussions, if any modifications to the program were needed, as well as what tailoring information specific to the class were needed (i.e., what should the inclusion/exclusion criteria be for the class, how can participants provide feedback, when to provide feedback, how often they wanted to provide feedback, and when they think the class should be modified on an individual level). The information from these sessions was used to create specific and comprehensive programming to be used in the next phase of the study (i.e., the pilot trial).

2.2 Student involvement and experiential learning

The experiential learning model used in the current study integrates the principles of iKT and co-design through the integration of trainees (e.g., undergraduate students, graduate students) from various academic backgrounds with complementary skillsets into research activities. Including trainees throughout the project enhances the co-design process by providing additional avenues of development via innovative solutions and enhanced learning. Meaningful engagement by trainees was a key aspect of the co-design process for this project, as it fostered a pragmatic and inclusive approach to the development of the PMP.

A core team composed of a post-doctoral fellow and two graduate students from professional programs (i.e., occupational therapy and physical therapy) worked collaboratively with undergraduate trainees. Six undergraduate trainees with varying skills and experiences from various disciplines (i.e., kinesiology, health sciences, medical sciences) were involved in the co-design process. In collaboration with the undergraduate trainees, the core team worked to advance the development of PMP and tailoring variables. To achieve this goal, the core group facilitated trial development activities and mentored undergraduate trainees throughout the various sub-projects associated with the overall research study (i.e., information gathering activities, working group sessions) as well as through the development of mobility programming.

In addition to the working group sessions described above, the undergraduate trainees involved in the project attended weekly check-in meetings facilitated by the core team to discuss pertinent agenda items related to ongoing trial activities, provide updates on overall project progress, and communicate any concerns about their tasks. Undergraduate trainees were assigned tasks and activities that aligned with their personal and professional goals and interests, as permitted by their capacities. Two of the undergraduate students experienced in creating and leading mobility programs helped develop the virtual Cognitive Cardio and Strength programs for the future phase of the project.

3 Results

Eight working group meetings were conducted with the first working group two sessions with the second working group and three one-to-one sessions, for a total of 13 sessions. This series of working group sessions resulted in the development of four mobility programs. Each working group session lasted between 30 min and 1.5 h. A brief summary of each of the first working group sessions is provided in Table 2. Information gathered from the second working group sessions and one-to-one sessions have been described below.

3.1 Types of programs developed

Based on the information provided throughout the working group sessions, four main mobility programs were developed. Two programs were adapted based on already available programs at the rehabilitation hospital. The first of these programs was a cognitive cardio class and the second was a functional strength class. The third program was a newly developed program, which will include a circuit style mobility training class for those with various mobility or functional skill goals. The fourth program that will be made available is an open gym format, where participants can come in and use various equipment and complete their own workouts (see Table 3 for descriptions of the PMPs).

3.2 Key aspects of personalization

With respects to logistics of the programs, participants in the first working group discussed having as many options available as possible. This included a mix of virtual and in-person classes, as well as the availability of asynchronous options. The timing of the classes was also discussed by the first working group, as individuals with different needs who would be attending the group would likely require different times (e.g., morning routines may be lengthy, younger individuals may be working and can't attend class during the day).

3.2.1 Onboarding

The onboarding process was extensively discussed by working group members. The resulting process can be found in Figure 1. Participants in the first working group described being able to self-refer to the mobility programs, but clinicians in the second working group felt that individuals should be medically cleared to participate. One of the key topics of discussion during this session was whether the individuals participating in the program required an attendant. The need for an attendant was identified as a key consideration by clinicians for inclusion or exclusion in the mobility programming. In addition to the need for an

TABLE 2 Brief overview of the first working group discussions by session.

Session number	Summary of discussions
1	Introduction to working group activities, purpose and goals of the group.
2	Participants in the working group spoke about logistical considerations such as virtual or in-person, whether instructors should be able-bodied and if that was the case, should they be accompanied by a PWLE. The inclusion of one-on-one time with instructors was also discussed. The group also began preliminary discussions about content, which included needing to have fun and enjoyable programming, how to ensure the programming was fun (e.g., via check-ins) as well as having a variety of options for people to chose from.
3	Both PWLE and the fitness instructors expressed interest in wanting to have a meeting one-on-one prior to classes beginning so the PWLE could share information about their condition and limitations. From the instructor perspective, instructors would like to get to know participants so that they can make modifications to the class and help them feel more prepared. With respect to the content of the onboarding process, PWLE talked about wanting to know about any potential barriers there may be to participating in the program. They felt strongly about getting to talk with instructors prior to beginning any program. Fitness instructors would prefer one-on-one sessions (like a trial class) so that potential participants could flag what worked and what didn't work throughout the class. Logistics were also discussed, particularly if the onboarding should be mandatory, how far in advance the process should start and to decide which on-boarding process would be best for the participant.
4	Participants discussed having levels of classes (e.g., beginner/more advanced) so people don't get discouraged. There was a lot of emphasis of having programs consider things that weren't necessarily physical like mental well-being. Working group members wanted to incorporate something to help with skills to alleviate and regular stress. The working group felt strongly about developing some sort of pool program to help people gain confidence in the water. Other suggestions for programming included a functional skills class, a general exercise literacy class, open gym/circuit training course, and ensure that some sort of social aspect incorporated. The social aspect was important in order to provide mental support and destress.
5	Trial cognitive cardio class. Participants generally found this to be a great program and felt that the class would meet the needs of the current project. The group discussed the logistics of having a hybrid model class (e.g., in person and online options), as well as asynchronous options (e.g., videos to review if participants could not attend class during class time). With respect to personalization, participants encouraged the research team to explore other options for the cognitive portion of the class. For example, rather than having just riddles, perhaps include trivia or visual puzzles depending on the needs of the participants to be determined at the beginning of the class.
6	Trial functional strength class. Working group participants felt that this class would meet the needs of a personalized mobility program and like the overall design of the class. The group felt that having different levels of classes would work well for this type of training with options to have asynchronous videos available. When asked about making this type of class a companion class to an in-person circuit style mobility training program, participants felt that this would exclude those who could not attend in-person. Logistics of hybrid style were discussed, and the group described the difficulties of using a hybrid style as it may isolate individuals who were joining virtually. Decisions around keeping the class entirely virtual were made to accommodate the majority of individuals. Preliminary discussions about onboarding and check-in modalities were initiated.
7	During this session, participants described liking the idea of having to complete a survey about their demographics and preferences prior to enrolling in a specific program. Participants also described wanting the option to have an open gym where they were not restricted by needed to attend specific class times that may not work with everyone's schedule. Logistics of the trial were also discussed (e.g., self-referral to the program, how many trial participants will there be at a time, who will be running sessions, etc.).
8	Participants during this session discussed wanting to have a booklet in order to track their progress over the course of their participation in the mobility programming. At the beginning of the booklet, an initial assessment would be included which would involve SMART goal setting. The participants then envisioned that the individuals taking part in the mobility programming could reflect on their goals each week and fill out surveys for program feedback. Instructors would also fill out surveys about how they feel the program is going. Participants in the working group session also discussed what areas they considered should be measured in order to determine if a program was successful. High level domains included quality of life, goal attainment, self-esteem, self-efficacy, and social connectedness.

attendant, clinicians also discussed that falls risk should be a factor when deciding if the program was appropriate for a participant. Other criteria for exclusion included whether a potential participant was able to accurately determine their limitations (e.g., lack of awareness of their challenges due to cognitive issues). Furthermore, if the participant could not determine their limitations on their own, they would require an attendant to remind them of their capabilities. This aligns with the clinicians thoughts about the process to enter the mobility programming, where the working group members described needing a referral to the program by a clinical team member.

As part of the on-boarding process, members in both working groups discussed using a survey to gather specific information about the participants who would be joining the mobility programming. Key aspects of the survey highlighted by both working groups and during the one-to-one sessions included information about participant's health conditions, communication preferences and importantly, their program preferences. Members in the first working group communicated that trying to fit the program to the participants preferences such as music or no music, group size, goals, amongst others, would be a key component of ensuring the program was personalized to the participant.

Based on the feedback of the first working group, the development of a booklet would be used from the beginning of the program and would be used throughout their involvement. At the beginning of the booklet, information gathered during the initial assessment would be included to track progress throughout the program. Members of the first working group also spoke strongly about having one-on-one sessions with instructors prior to the beginning of the program to ensure that their safety concerns would be met. This was the basis for the decision about including an initial assessment.

3.2.2 Within program tailoring

Several working group sessions revolved around the participants of a personalized mobility program ability to provide feedback to the instructors throughout the program. Discussions included when to provide feedback and how to provide feedback. The modality of

TABLE 3 Descriptions of personalized mobility programming.

Name of program	Method of program delivery	Description of program
Cognitive Cardio	Virtual	Cognitive Cardio is a moderate- to high-intensity class with an emphasis on cardio. This class involves answering two riddles and one trivia question while completing a cardio exercise (e.g., marching, seated or standing). For each riddle/trivia the participant will have a 45-second buffer before they can shout out the answer so that everyone can have a chance to think it through. After 3 riddles/trivia have been answered, there will be a break before moving on to the next exercise. There will be a total of five exercises with two riddles and one trivia question each. This class offers variations that incorporate lower body movement for those who are interested, and all exercises are modifiable to meet the level of physical function of participants. Equipment is not needed for this class and music is not played in this class to allow less distractions while thinking about the riddles.
Strength Class	Virtual	Strength Building aims to program that focuses on building strength to make it easier to complete everyday tasks and lower the risk of injury. This class focuses on improving upper and lower body and core strength. The class runs for 60 min once a week for six weeks. The class takes place online. Music is not played in this class. Each class will begin with a warm-up, followed by rehearsal moves that will go over the exercises that will be completed during the class. Exercises will be chosen based on participants goals and to introduce participants to new exercises that they will get a chance to practice bi-weekly. Participants will alternate between two routines that will be completed every other week.
Mobility Circuit Group	In-person	Mobility Skills Circuit Group is a skills-based program that focuses on improving one's ability to move more freely and easily, specifically learning skills to enhance your use of a mobility aid, transfers, endurance, and activities of daily living/instrumental activities of daily living. Our mobility influences our ability to do the activities of daily living that we enjoy. This class focuses on improving range of motion, balance, coordination, fine motor skills, endurance, gait, standing, walking, transfers and self-care. The class runs once a week for six weeks. The class is completed in-person in a small group. Music is not played in this class. There is a 90-minute social component. Each class will begin with a warm-up, followed by four stations (mobility, transfers, endurance, and activities of daily living/instrumental activities of daily living (ADLs/IADLs).
Open Gym	In-person	Open Gym offers a dynamic, self-guided fitness experience suitable for individuals of all mobility and strength levels. This program benefits those familiar with exercise equipment and workout routines. Beginners are not left behind, as our skilled student trainers can provide comprehensive introductions to gym equipment. Under the watchful eye of these trainers, you can progress at a comfortable pace, focusing on personal fitness objectives such as enhancing strength, boosting endurance, or improving flexibility. Whether you prefer to exercise independently, seek guidance, or engage with fellow fitness enthusiasts, our gym fosters a welcoming environment for all. We actively encourage social interactions among participants, creating a vibrant community atmosphere that enhances the overall workout experience.

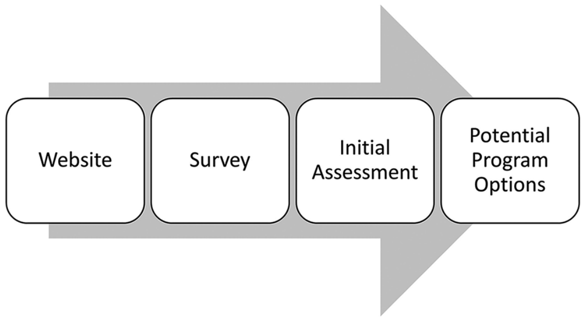

FIGURE 1
Onboarding process. (1) Website: potential participants will be directed to a website where they can review the available programming. Written descriptions and video introductions will be available for individuals to review. (2) Survey: if the individual is interested, they will be asked to complete a short survey in order to better understand their needs and goals. (3) Initial assessment: The research team will review the answers of the survey and come up with a set of programming options. The research team will meet with the interested individual to go over their responses and discuss their goals and mobility needs more in depth. (4) Potential program options: During the session, the research team member will discuss the potential programming options with the individual and determine which programs will best meet their needs. Once the individual is happy with the selected programs, they will be enrolled in the 6 week program.

feedback provisions was dependent on the type of program being delivered. For example, during a low impact class such as the cognitive cardio class, the working group members did not feel as though weekly feedback was necessary. Instead, a possible option would be to have participants fill out a survey about how the program is going and if participants felt they were not meeting their goals or were having problems this would be flagged to the instructors for follow-up.

When asked about the structure for program reflection, the clinicians in the second working group discussed several key considerations when curating resources for the booklet described by the first working group. Clinicians described using Likert type scales or symbols instead of open spaces for writing for those who may have trouble with writing, offering both hard copy and digital formats for those who may use assistive technology as well as interpreters where available. Thoughts on resources for the booklet included an education section about how to set SMART goals, and a goal attainment scale such as the Goal Attainment Scaling (GAS) (16).

Decisions about when the programs should be stopped were discussed by participants in the first working group. Members from the first working group felt that participation in the mobility programming should be stopped if the participant was having physical problems participating in the exercises or the program was no longer meeting the goals of the participant.

4 Discussion

The co-design process that was undertaken in the current study highlights the effectiveness of using such an approach to develop PMP and related tailoring variables. This paper fills a gap in the current literature, where articles seldom describe how the personalization and tailoring process is determined (1). It is critical to be transparent about the processes used to determine personalization in order to ensure that the programming can be easily replicated (17, 18). Key take-aways from this work include how to incorporate perspectives from a broad range of stakeholder groups, including PWLE, clinicians, and researchers. This paper also provides insights on how to ensure meaningful engagement in the development of research programs (e.g., trial classes).

4.1 Strengths of our approach

There are a number of strengths to using the collaborative approach to adaptive intervention design described here. Our co-design process followed the well established iKT principles set out by the University of British Columbia, for integrating PWLE experience into all aspects of the research (5, 6). Previous literature suggests that interventions (which in the case of the current article is the PMP), that are developed via co-design are more likely to be to be acceptable to providers and end users, which increases the likelihood of adoption (19). To enhance the comprehensiveness of our approach and gather diverse perspectives, we recruited a wide range of individuals with different neurological conditions such as stroke, multiple sclerosis, brain injury, and spinal cord injury. Additionally, we included front line clinicians and students from various disciplines to further enrich our project. The diversity of members across our working groups and one-to-one sessions ensured that the information we gathered was representative of the context within which the PMP will be conducted. Furthermore, the use of working groups and individual sessions provided the opportunity to get direct feedback on the suggested programming and other trial components (e.g., onboarding, website design, booklet, etc.), which will help to ensure that the mobility programming to be used in the pilot trial will likely be relevant and applicable to a diverse group of participants with varying mobility needs.

Also unique to our approach is the involvement of students and the experiential learning. Involving students from various disciplines not only provided them with an opportunity to put their theoretical knowledge into practice, but provided our team invaluable perspectives on the development of the different aspects of the program.

4.2 Limitations of our approach

While we aimed to undertake as rigorous a process as possible, this approach does not come without it's limitations. The main limitation was logistical in nature, mainly involving the scheduling of the working groups. First, given the schedules of clinicians, we were unable to have them attend the working group sessions with the PWLE and fitness instructors. While it would have been helpful to have the clinicians attend multiple sessions, we were able to get highly relevant information from the times were able to speak with them directly. Another limitation with scheduling was attempting to coordinate a relatively large number of people with different schedules, which delayed the initial start of the process. However, once we had found a time that worked on a weekly basis for the first working group members, scheduling was less of an issue. For those individuals who expressed interest in participating but were unable to join our groups, we provided additional opportunities for participation (e.g., the second working group, individual sessions with members). While this did create more work for the research team, these sessions were invaluable to the process to ensure we captured as many perspectives as possible to inform the PMP and tailoring variables.

Similar to qualitative focus groups, there are limitations of facilitating these types of groups (e.g., managing differing personalities, ensuring all participants are able to share their thoughts). While the facilitators of the working groups did their best to engage all members, it is possible that some members were unable to share their thoughts or did not feel comfortable in this type of setting. To best address this challenge, the research team offered the working group members the option to share their opinions via email after the working group sessions. In addition to this, the notes of each meeting were sent to the members and the members were encouraged to let the research team know if there was anything missing from the notes or if there was anything they would like to add.

A final limitation of this work was the lack of evaluation of meaningful engagement of our working group members. While we undertook a number of strategies to ensure that our working group members were able to participate as fulsomely as possible, there is a possibility that some participants may not have felt valued or felt their participation was not valued. Future work should aim to evaluate the strategies used in the co-design process to ensure that participants feel engaged throughout the process.

4.3 Implications

The current paper provides a guideline for future work that aims to develop programming that is personalized to the needs of the persons with mobility impairments due to various neurological conditions. We encourage those who are developing similar programming to be as transparent as possible about their processes for determining personalization and tailoring variables. While the current article is focused on mobility programming, the co-design process described here is likely applicable to the development of other interventions that include personalization and tailoring. Despite the limitations of using and facilitating a co-design process, the rigour that it provides to ensuring that the resulting programming is applicable and relevant to the target population is invaluable.

5 Conclusion

Overall, the co-design process described here resulted in an initial set of PMP for persons with varying levels of mobility impairments. This paper fills multiple gaps in the current literature, including a lack of transparency about how tailoring variables are developed and how stakeholders are included in program design. The process undertaken throughout the pre-research activities provides an example of how to promote meaningful engagement in the co-design of PMPs and associated tailoring variables. The next phase of the project will involve a pilot trial to better understand the feasibility of implementing the mobility programs developed, including the acceptability to a larger range of individuals with mobility impairments.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

SC: Conceptualization, Formal Analysis, Writing – original draft, Writing – review & editing. OC: Writing – original draft, Writing – review & editing. DL: Writing – original draft, Writing – review & editing. AS: Writing – original draft. JS: Writing – review & editing. DW: Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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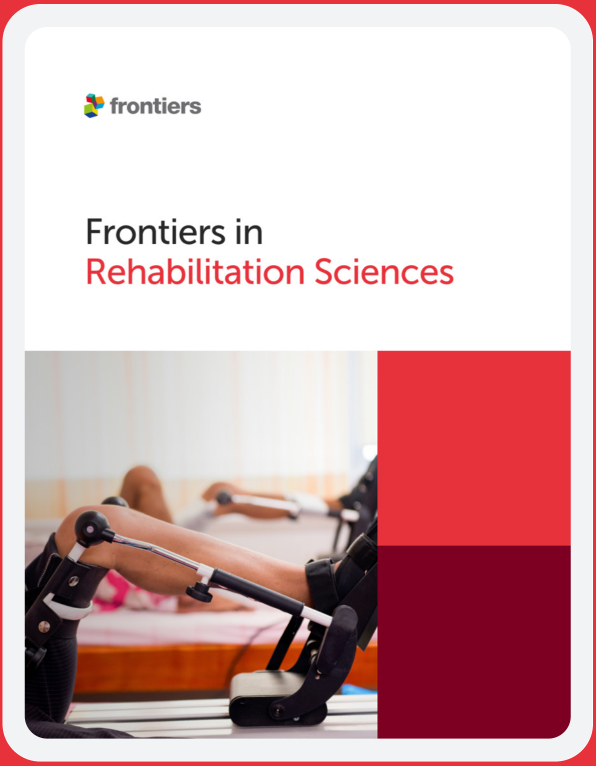

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