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Consolidated Principles for Equitable and Inclusive Digital Health and Virtual Care Co-Design

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ABSTRACT

Digital health and virtual care (DH/VC) interventions have been rapidly transforming healthcare systems, offering enormous potential to bridge gaps in healthcare access and quality. However, these interventions have also exacerbated existing inequities. Partnering in partnership with patients, caregivers and community members in co-design is essential to ensure that DH/VC experience perspectives since DH/VC interventions have the potential to exacerbate existing inequities and create new ones if not done thoughtfully. We propose a preliminary set of principles to guide co-design of DH/VC interventions to ensure they are equitable and inclusive.

INTRODUCTION

Digital health and virtual care (DH/VC) interventions have the potential to revolutionize the Canadian healthcare system by offering a more cost-effective, convenient, and accessible way to provide care to patients and communities (Abernethy et al. 2022; Murray et al. 2016). Despite the promise of DH/VC in addressing healthcare challenges, there is a growing concern that these interventions may exacerbate existing inequities and create new ones if they do not actively work to address them (Lee et al. 2021; Reed et al. 2019). Many DH/VC interventions have been developed without adequate consideration of the needs and preferences of the communities they are intended to serve (Ellahi et al. 2022; Shaw et al. 2021). This reduces the chance that such innovations will respond to the needs and preferences of the communities they are intended to serve and may prevent them from the patient-centered care that is a key component of high-quality healthcare (Institute of Medicine 2001).

Patient-centered care is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, caregivers and communities (Institute of Medicine 2001). Co-design is a key method for DH/VC developers to achieve patient-centered and patient-oriented DH/VC interventions (Sanders and Stappers 2008). Co-design is a collaborative process that brings together people with different perspectives to jointly design, develop and improve products, services or systems (Sanders and Stappers 2008).

> **Key Point**
>
> Co-design has emerged in the DH/VC literature as one solution for developing more patient-centered DH/VC interventions, with special consideration for the needs of equity-deserving groups (Ellahi et al. 2022; Shaw et al. 2021). Co-design is a collaborative process that brings together people with different perspectives to jointly design, develop and improve products, services or systems (Sanders and Stappers 2008). Co-design is a key method for DH/VC developers to achieve patient-centered and patient-oriented DH/VC interventions (Sanders and Stappers 2008). Co-design can be used to guide many different aspects of the development of DH/VC interventions, including the selection of which DH/VC interventions to develop, the design of the DH/VC intervention itself, and the evaluation of DH/VC interventions.

Co-design approaches and principles

Co-design has emerged in the DH/VC literature as one solution for developing more patient-centered DH/VC interventions, with special consideration for the needs of equity-deserving groups (Ellahi et al. 2022; Shaw et al. 2021). Co-design is a collaborative process that brings together people with different perspectives to jointly design, develop and improve products, services or systems (Sanders and Stappers 2008). Co-design is a key method for DH/VC developers to achieve patient-centered and patient-oriented DH/VC interventions (Sanders and Stappers 2008). Co-design can be used to guide many different aspects of the development of DH/VC interventions, including the selection of which DH/VC interventions to develop, the design of the DH/VC intervention itself, and the evaluation of DH/VC interventions.

> **Key Point**
>
> **Key 1: A vignette. The role of the patient/caregiver in DH/VC co-design processes**

After the COVID-19 pandemic, there's primary care clinic has been advertising that they plan to offer more virtual care options for patients. And there is optimistic about virtual care; however, she wants to ensure that the virtual care options will be accessible to her and her family. She is particularly concerned about her 80-year-old mother, who lives with her family and has limited mobility. She wants to ensure that her mother can still receive the care she needs without the virtual care appointments to translate. This is challenging as her mother does not speak English and she is one of her primary caregivers.

However, even with a high budget and strong leadership, Maria finds the process of virtual care promising as it is necessary to get to the clinic and it can save them time. Maria has a lot of ideas for how virtual care could be set up to meet the needs of her family and her community. She would like to see the clinic ask patients to know about her ideas, concerns, and possible solutions?

Maria's clinic has been working on implementing virtual care for the past two years. She is concerned that the clinic will not deliver high-quality care. They have been using a virtual care platform that is not user-friendly and has a lot of technical issues. Maria is also concerned that the clinic is not listening to patients and the vendor are unsure how to capture the needs of the different patients who use the clinic and represent a community (Primary Care Clinic). The clinic has been using a virtual care platform that is not user-friendly and has a lot of technical issues. Maria is also concerned that the clinic is not listening to patients and the vendor are unsure how to capture the needs of the different patients who use the clinic and represent a community (Primary Care Clinic).

DH = digital health; VC = virtual care.

AIMS AND OBJECTIVES

This commentary offers consolidated best practice principles to guide equity-informed DH/VC co-design to partner more effectively with people with lived experience, including those from equity-deserving groups. These consolidated principles were developed by a group of researchers, innovators and people in the health workforce during the planning, development delivery and evaluation of DH/VC interventions to ensure that DH/VC interventions reflect the needs and preferences of the people they are meant to serve.

Consolidation of principles for equitable and inclusive DH/VC co-design

In this section, we present a set of principles for co-designing equity-informed DH/VC interventions that meaningfully integrate lived experience perspectives of patients, caregivers and community members. These principles were developed by a group of researchers, innovators and people in the health workforce during the planning, development delivery and evaluation of DH/VC interventions to ensure that DH/VC interventions reflect the needs and preferences of the people they are meant to serve.

Table 1. Co-design frameworks: A summary

Author (year)	Title	Co-design process framework components
Bird et al. (2022)	A generative co-design framework for healthcare innovation: Development and application of an end-user engagement framework	1 Pre-design • Contextual inquiry (observational fieldwork and informational interviews) • Participatory and training (participant and facilitator selection, preparatory materials and techniques)
		2 Co-design • Framing the issue (root experiences and what must change) • Ideation (visioning, reimagining needs, challenges, opportunities and future state solutions) • Sharing ideas (presentations of generative design work and appropriate inquiry)
		3 Post-design • Data analysis (description, organizing and coding) • Requirements' translation (action items)
Voorheis et al. (2022)	Maximizing the value of patient and public involvement in the digital health co-design process: A qualitative description study with design leaders and patient public partners	1 Preparation and planning • Recruit diverse patient partners • Select multiple co-design methods • Reconsider co-design planning tools • Create a co-design communication plan
		2 Product and experience design • Product design (co-design the user experience, behavioural supports and in-person activities) • Implementation design (co-design how users will perceive a product, how much the solutions will adapt the product)
		3 Adaptation and improvement • Co-design equity-based data collection and evaluation • Co-design how the solution will be tailored • Co-design a sustainability plan

While these co-design frameworks offer a helpful starting point, they do not explicitly capture perspectives from equity-deserving groups with lived experiences (including but not limited to racialized and communities) and do not suggest specific principles to guide co-design to address inequities. Therefore, using these frameworks as a backbone, we overlay principles from published research that discuss equity-informed approaches for healthcare innovation design (Table 2). Specifically, we will use basic principles of co-design from Bird et al.'s framework (2022), as well as principles from Voorheis et al.'s framework (2022) that are specific to DH/VC co-design. We will also use principles from Sanders and Stappers' (2008) co-design framework, as they are one of the most widely cited digital health frameworks and finally, by Tremblay et al. (2020) their framework on principles for participatory practices in patient-oriented research. These papers were purposely sampled because they are seminal papers in the field, written by authors who have rich experience in co-design.

Table 2. Considerations from published articles to support meaningful engagement and partnership in inform equitable and inclusive DH/VC co-design

Author (year)	Title	Considerations to promote equitable DH/VC co-design as shared by the article authors
Sasseri et al. (2020)	Building equitable patient partnerships during the COVID-19 pandemic: Challenges and key considerations to address in practice and policy	Build inclusive and diverse patient partnerships • Use an equity-oriented approach to engagement • Co-build sustainable safe spaces to engagement • Consider issues of accessibility • Build capacity one relationship at a time • Go to them
Kuluski et al. (2019)	Twelve principles to support caregiver engagement in health care policies and health research	Policies and structures • Use policy levers, incentives and tools to support engagement • Make structural changes Culture and mindset • Face fears, do not wait for perfection • Be open to learning from and with and engage partners • Define what quality engagement means • Avoid tokenism by including more than the "usual suspects" • Address language and power issues by creating comfortable spaces to open up Procedures • Engage early during the problem identification stage • Listen and act on what you hear from partners • Meaningfully measure, do not just survey people and focus on capturing stories • Share learnings by constantly re-evaluating engagement to be of maximum benefit
Chauhan et al. (2021)	Optimizing co-design with ethnic minority communities	Ensure that diverse, seldom-heard groups are invited • Liaise with community representatives and support groups • Employ peer-led community engagement Meet partner needs and allocate resources • Use multilingual facilitators • Arrange financial remuneration • Identify technical, access and support needs • Schedule around cultural and religious practices Enable a diversity of contributions • Co-develop terms of reference • Co-develop workshop design, content and scheduling • Contribute to the evaluation of the service process
Brewer et al. (2020)	Back to the future: Achieving health equity through health information and digital health	Design and implement digital health for marginalized communities • Increase recruitment and retention of diverse populations throughout the research and development process • Leverage established leaders and trusted networks in communities • Understand the social context of potential users, including social determinants of health and digital determinants • Integrate community engagement into user-centred design practices • Understand community partnerships and their role in community capacity building • Plan for appropriate amount of time and resources for community engagement for intervention development and sustainability
Noorbergen et al. (2021)	Using co-design in mobile health system development: A qualitative study with experts in co-design and mobile health system development	Address the challenges in designing digital health systems • Understand participant vulnerabilities and diversity • Plan for extensive health behaviour change • Plan for multiple engagement sessions • Ensure co-design participants have an authentic, empathetic understanding of the context • Plan for immersion into the mobile health ecosystem by identifying key partners and processes • Identify and involve poor-design advocates who can act in implementation, champion and sustainment • Use health-specific evaluation criteria to understand impacts on the health system and end users • Produce usage data to understand impact
Tremblay et al. (2020)	Engaging Indigenous patient partners in patient-oriented research: Lessons from a one-year initiative	Build meaningful partnerships with Indigenous patient partners • Initiation of a partnership (need anchor in their community and build on existing relationships and networks, and be flexible in engagement) • Shared development (build trusting relationships and emphasize shared research for patients and communities) • Capacity building (ensure a shared understanding of the patient partner's role and provide training and support for patient partners)
		• Involvement in research (offer diverse opportunities for engagement, be reflective and flexible in all aspects of involvement and value patient involvement and contributions to the project)

DH = digital health; VC = virtual care.

This table is also available online here.

Figure 1 presents an overview of the best practice principles from the above work, offering a new contribution to the field as the Principles for Equitable and Inclusive Digital Health Co-Design framework. This novel framework emphasizes equity-informed principles for engaging those with lived experience in each phase of the DH/VC co-design process. The framework is also complemented by a checklist (Table 3) that can be used by those who will be co-designing DH/VC interventions to ensure they are equitable and inclusive.

Figure 1: The Principles for Equitable and Inclusive Digital Health Co-Design Framework

A more detailed version of the figure is available online here.

DISCUSSION

Using Bird et al.'s (2022) and Voorheis et al.'s (2022) co-design process frameworks as a starting point, this commentary demonstrates how best practice principles related to equity-informed engagement and design can be applied throughout the co-design process. The Principles for Equitable and Inclusive Digital Health Co-Design framework and checklist can be used to guide many different aspects of the development of DH/VC interventions, including the selection of which DH/VC interventions to develop, the design of the DH/VC intervention itself, and the evaluation of DH/VC interventions.

A noteworthy finding from the above best practice principles for equity-informed DH/VC co-design is that there is an imbalance of principles across the different phases of co-design. For instance, most principles focus on pre-design, offering advice on how to build trusting relationships and prepare for co-design (Bevan et al. 2020; Chauhan et al. 2021; Kuluski et al. 2019; Noorbergen et al. 2021; Sasseri et al. 2020; Tremblay et al. 2020). Only a few principles focus on co-design and post-design. This is an important finding as it suggests that there is a gap in the literature on how to engage those with lived experience in co-design and post-design activities, as well as this as an important gap that needs to be addressed in future works. Key 1 presents a new vignette of how Maria and her family could be engaged in co-design and post-design activities.

> **Key 2: A new vignette: An equity-informed DH/VC co-design process**

Maria's clinic's team and vendor partner have decided to engage with patients in co-design work before rolling out their new virtual care solution. Given the clinic's diverse patient population, they asked the Principles for Equitable and Inclusive Digital Health Co-Design framework to guide their approach.

During the pre-design phase, the clinic team and vendor partner began the co-design process by discussing the project with trusted local community leaders, mapping out the diverse patient population and their needs and preferences for virtual care. Using the Principles for Equitable and Inclusive Digital Health Co-Design framework, they developed an appropriate budget and timeline. During the co-design phase, the clinic staff hired Maria and other patients to be co-design partners. Maria was paid for her participation and was provided with childcare support. The clinic staff also offered flexible co-design sessions, including in-person and online sessions, and ensured that all materials were translated into Maria's preferred language. During the phase call, Maria learns that the clinic would like to have her thoughts and perspectives on the virtual care platform that they are considering implementing. Maria is excited to participate in co-design as she has a lot of ideas for how virtual care could be set up to meet the needs of her family and her community. She is also interested in what it is expert and that the clinic will offer her childcare reimbursement for meaningful participation.

During the co-design phase, the clinic staff hired a co-design facilitator with experience in co-design sessions with patients to engage engagement by using peer-led facilitators. During the co-design sessions, Maria feels heard and understood as the co-design facilitator clarifies how their feedback will be used to refine the virtual care platform. The co-design facilitator also ensures that Maria's concerns are addressed and that she has the opportunity to provide input on the design process. The co-design sessions were also co-designed with community members to ensure that they were culturally appropriate and meaningful to the community (Primary Care Clinic). Examples of what it is expert and that the clinic will offer her childcare reimbursement for meaningful participation. Maria's clinic has been using a virtual care platform that is not user-friendly and has a lot of technical issues. Maria is also concerned that the clinic is not listening to patients and the vendor are unsure how to capture the needs of the different patients who use the clinic and represent a community (Primary Care Clinic).

In the post-design phase, the clinic staff hired a co-design facilitator with experience in co-design sessions with patients to engage engagement by using peer-led facilitators. During the co-design sessions, Maria feels heard and understood as the co-design facilitator clarifies how their feedback will be used to refine the virtual care platform. The co-design facilitator also ensures that Maria's concerns are addressed and that she has the opportunity to provide input on the design process. The co-design sessions were also co-designed with community members to ensure that they were culturally appropriate and meaningful to the community (Primary Care Clinic). Examples of what it is expert and that the clinic will offer her childcare reimbursement for meaningful participation. Maria's clinic has been using a virtual care platform that is not user-friendly and has a lot of technical issues. Maria is also concerned that the clinic is not listening to patients and the vendor are unsure how to capture the needs of the different patients who use the clinic and represent a community (Primary Care Clinic).

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Overall, the consolidation of best practice principles for equitable and inclusive DH/VC co-design presented in this paper offers a way for the DH/VC field to ensure that future design processes will adequately account for the needs of equity-deserving groups.

Healthcare Excellence Canada resources and educational opportunities

In addition to the principles discussed above, Healthcare Excellence Canada (Excellence Canada) has DH/VC design teams understand, to create and adopt best practices to ensure that solutions capture issues that matter most for those with lived experience, including equity-deserving people and communities. Excellence Canada has a number of resources and educational opportunities that can help DH/VC design teams understand, to create and adopt best practices to ensure that solutions capture issues that matter most for those with lived experience, including equity-deserving people and communities. Excellence Canada has a number of resources and educational opportunities that can help DH/VC design teams understand, to create and adopt best practices to ensure that solutions capture issues that matter most for those with lived experience, including equity-deserving people and communities, builds capabilities and catalyzes policy change to help shape a future where everyone in Canada has safe and high-quality healthcare.

Listed below are several relevant HEC resources for equity-informed DH/VC co-design:

- *How to Successfully Engage Patients and Families 10 Lessons Learned from Patient and Family Advisors* is a resource that outlines 10 insights about what worked to help patients and family advisors feel engaged and valued in healthcare improvement.
- Engagement Opportunities: Here's a list of Excellence Canada's current engagement opportunities, including our Virtual Care Toolkit engagement (HEC 2023a). The toolkit includes considerations and example questions to guide partnerships with patients to co-design virtual care solutions.
- Capacity Building Offerings: Excellence Canada offers capacity building opportunities to help build equitable and inclusive e-Healthcare (HEC 2022b). The e-Healthcare Foundations course is designed to help build capacity of people with lived experience to engage in DH/VC co-design and to apply approaches for including those who have traditionally been excluded from patient engagement because of systemic barriers.
- Innovating Healthcare Together: A Guide to Co-Creation (HEC 2022a). This guide is a resource that offers practical guidance to foster respectful partnerships between people with lived experience and healthcare providers, leaders and researchers to co-create healthcare improvements and innovations (Patel et al. 2022). A related resource includes *A Journey We Walk Together: Strengthening Indigenous Cultural Competency in Health Organizations*, a primer for health organizations to build and enhance Indigenous cultural competency.

Additional resources that might be relevant to DH/VC design teams are listed as follows:

- *Patient Oriented Research Guidebook: A Child Health* is a series of three books to help build understanding and skill to lead patient-oriented research in child health including foundations for patient engagement (POWCH n.d.).
- *Patient Engagement Guidebook* (SickKids n.d.) provides information on how to register for a series of four free online modules to build skills to conduct patient-oriented patient research (SickKids n.d.).
- Learning Together: *The Use of Simulation to Enhance and Enable Authentic and Meaningful Research Partnerships* is a simulation-based educational program designed to support patients, families and the broad research community to develop skills and confidence in working together in research partnerships (Bevan et al. 2020).

CONCLUSION

In conclusion, consider the following to co-design equity-informed DH/VC interventions with patients, caregivers and communities:

- Use equity-focused co-design principles throughout the entire DH/VC development process, including during pre-design and post-design.
- DH/VC can design work take participants (i.e., patients, caregivers and communities – as well as researchers, innovators, designers – and people in the health workforce). Use the Principles for Equitable and Inclusive Digital Health Co-Design framework and checklist when planning a virtual care co-design project to guide inclusive questions and meaningful outcomes.
- Employ strategies to ensure diversity in the voices of people with lived experience and the communities that the DH/VC intervention is meant to serve. Through co-design work, be mindful of the power dynamics between participants and the co-design team and how to mitigate them.
- Continue to engage with patients, caregivers, communities and people in the healthcare workforce after the DH/VC solution is implemented, which will help ensure that DH/VC interventions continue to meet the needs of those they serve.

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